

**IDENTIFYING THE INTERPERSONAL COMMUNICATION COMPONENTS OF
BREAST CANCER CARE PATIENT NAVIGATION**

by

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University of Pittsburgh, 2018

Background: Patient navigation is an increasingly popular tool used in healthcare to address disparities in cancer care. Interpersonal communication is considered a critically important construct in patient navigation, although it is understudied. Moreover, the patient-navigator relationship may be influenced by the interpersonal communication skills and behaviors of the patient navigator. The primary goal of this dissertation research was to explore the perspectives of key stakeholders (patients, patient navigators and patient navigator administrators) on the interpersonal communication components of breast cancer care patient navigation and the relationship of these components to the patient-navigator relationship.

Methods: This study employed concept mapping, an innovative community-engaged mixed method approach that produces pictorial views of how concepts are interrelated. Key stakeholders participated in study planning and participants completed the concept mapping activities, including brainstorming, sorting, rating, and interpretation. Brainstorming, sorting and rating were completed online. Interpretation took place through in-person sessions separated by participant group.

Results: Thirty-one participants including patients with breast cancer, breast cancer patient navigators and patient navigator administrators from Western Pennsylvania participated. During brainstorming, 121 non-unique items were generated. These statements were combined into one master list of 85 items. After the sorting and rating step, the 85 items were grouped into a six-cluster concept map. Through the group consensus process during the interpretation sessions, the

six clusters were named. Diagrams produced by participants noted that all the identified components were essential to patient navigation, but *Skills to Build Trust and Patient Centered Relationships* and *Maintain Professional, Positive and Thoughtful Communication and Care* were the most impactful components for promoting the patient-navigator relationship. Results of the rating step showed no notable differences between groups with participants rating *Empathetic, Comprehensive and Compassionate Support, Bridge to Clinical Education and Supportive Resources, and Ongoing Individualized Coordination of Care* as the most important components for facilitating the patient-navigator relationship.

Conclusion: These findings have both identified and operationalized the emerging interpersonal skills and behaviors of patient navigators in breast cancer care. These identified components can inform the patient navigation role description, competencies, and the development of curriculum for training and metrics for evaluation.

TABLE OF CONTENTS

PREFACE.....	XIV
1.0 PROPOSAL INTRODUCTION.....	1
1.1 SPECIFIC AIMS	2
1.2 BACKGROUND AND SIGNIFICANCE.....	2
1.2.1 Background and Significance	2
1.2.2 Patient Navigation Development.	3
1.2.3 Logistical Interventions and outcomes of patient navigation.....	5
1.2.4 Relational components of patient navigation.....	6
1.2.5 Patient-navigator relationship.....	6
1.2.6 Interpersonal communication in patient navigation.....	8
1.2.7 Community-engaged approach.....	9
1.3 INNOVATION.....	11
1.4 PRELIMINARY STUDIES.....	12
1.4.1 Evidence to support the need for further clarification of the patient navigator role.....	12
1.4.2 Evidence for the role of the patient-navigator relationship.....	16
1.4.3 Evidence to support potential role of patient navigation in addressing economic hardship.....	17
1.4.4 Stakeholder engagement plan.....	18
1.5 RESEARCH DESIGN AND METHODS.....	19
1.5.1 Design.....	19

1.5.2 Setting.....	20
1.5.3 Population.....	20
1.5.4 Sample.....	22
1.5.5 Sampling Procedures.....	22
1.5.6 Data Collection.....	25
1.5.7 Analysis Plan.....	29
1.5.8 Interpretation.....	31
1.5.9 Rigor and Trustworthiness.....	32
1.6 STUDY LIMITATIONS AND ALTERNATIVE APPROACHES.....	33
1.7 HUMAN SUBJECTES.....	34
1.8 RESEARCH PARTICIPANT RISK AND PROTECTION.....	35
1.8.1 Human Subject Involvement.....	35
2.0 SUMMARY OF STUDY	38
2.1 PROPOSAL MODIFICATIONS	39
2.2 CONCLUSIONS, IMPLICATIONS FOR NURSING AND FUTURE STUDIES.	40
3.0 MANUSCRIPT #1: POWER AND PRIVILEGE: A CRITICAL ANALYSIS OF INTERPERSONAL COMMUNICATION IN HEALTHCARE.....	43
3.1 ABSTRACT.....	43
3.2 BACKGROUND.....	44
3.3 METHODS.....	45
3.4 RESULTS.....	46
3.4.1 Definitions of the Concept.....	46
3.4.2 Defining Attributes.....	47

3.4.2.1 Verbal and Nonverbal Communication.....	48
3.4.2.2 Communication Styles.....	49
3.4.2.3 Patient-Centeredness.....	50
3.4.3 Subdimensions of the Concept.....	51
3.4.4 Antecedents.....	53
3.4.5 Consequences.....	54
3.4.6 Implications for Practice.....	55
3.5 CONCLUSION.....	57
4.0 MANUSCRIPT #2: EXPLORING STAKEHOLDER EXPERIENCES WITH INTERPERSONAL COMMUNICATION IN PATIENT NAVIGATION: A BRIEF REPORT.....	59
4.1 ABSTRACT.....	59
4.2 BACKGROUND.....	60
4.3 METHODS.....	61
4.4 RESULTS.....	62
4.4.1 Support.....	62
4.4.2 Personalization.....	63
4.4.3 Responsiveness.....	64
4.4.4 Navigator Characteristics.....	64
4.5 DISCUSSION.....	65
5.0 MANUSCRIPT #3: USING CONCEPT MAPPING TO EXPLORE INTERPERSONAL COMMUNICATION COMPONENTS OF PATIENT NAVIGATION IN BREAST CANCER CARE.....	67

5.1 ABSTRACT.....	67
5.2 BACKGROUND.....	68
5.3 METHOD.....	71
5.3.1 Design.....	71
5.3.2 Sample and Setting.....	72
5.3.2.1 Recruitment.....	72
5.3.3 Data Collection.....	73
5.3.3.1 Brainstorming.....	74
5.3.3.2 Sorting and Rating.....	74
5.3.4 Data Analysis.....	75
5.3.4.1 Interpretation.....	76
5.4 RESULTS.....	77
5.4.1 Participant Characteristics.....	77
5.4.2 Interpersonal Communication Components.....	79
5.5 DISCUSSION.....	87
5.5.1 Conclusion.....	92
6.0 MANUSCRIPT #4: STAKEHOLDER PERSPECTIVES ON IDENTIFIED INTERPERSONAL COMMUNICATION COMPONENTS OF PATIENT NAVIGATION AND THE PATIENT-NAVIGATOR RELATIONSHIP IN BREAST CANCER CARE.....	94
6.1 ABSTRACT.....	94
6.2 BACKGROUND.....	95
6.3 METHODS.....	97

6.3.1 Design.....	97
6.3.2 Setting and Sample.....	98
6.3.3 Data Collection.....	99
6.3.3.1 Brainstorming.....	99
6.3.3.2 Sorting and Rating.....	100
6.3.4 Data Analysis.....	100
6.3.4.1 Core Analysis.....	100
6.3.4.2 Interpretation Sessions.....	101
6.4 RESULTS.....	102
6.4.1 Naming and Discussion of the Six Clusters.....	104
6.4.1.1 Empathetic, Comprehensive and Compassionate Support.....	106
6.4.1.2 Skills to Build Patient Centered Trust and Relationships.....	106
6.4.1.3 Bridge to Clinical Education and Supportive Resources.....	107
6.4.1.4 Ongoing Individualized Coordination of Care.....	108
6.4.1.5 Personalized Patient Care through Assessment and Communication.....	109
6.4.1.6 Maintain Professional, Positive and Thoughtful Communication and Care.....	110
6.4.2 Relationships Between Clusters and the Patient-Navigator Relationship...	111
6.4.2.1 Patient Perspectives.....	114
6.4.2.2 Patient Navigator Perspectives.....	114
6.4.2.3 Administrator Perspective.....	115
6.4.3 Identified Action Items.....	115
6.5 DISCUSSION.....	116

6.5.1 Strengths and Limitations.....	119
6.5.2 Conclusion.....	119
APPENDIX A: PERMISSION LETTER AND PRELIMINARY WORK MANUSCRIPT #1.....	121
APPENDIX B: PERMISSION LETTER AND PRELIMINARY WORK MANUSCRIPT #2.....	122
APPENDIX C: IRB APPROVAL FOR STAKEHOLDER ENGAGEMENT STUDY.....	123
APPENDIX D: IRB APPROVAL FOR DISSERTATION STUDY.....	124
APPENDIX E: PATIENT RECRUITMENT FLYER.....	125
APPENDIX F: PATIENT NAVIGATOR AND ADMINISTRATOR RECRUITMENT FLYER.....	126
APPENDIX G: DEMOGRAPHIC QUESTIONNAIRE.....	127
APPENDIX H: PATIENT-NAVIGATOR RELATIONSHIP SCALE.....	128
BIBLIOGRAPHY.....	129

LIST OF TABLES

Table 1. Concept mapping activities and associated study aim.....	25
Table 2. Description of rating scales and patient navigation outcomes.....	28
Table 3. Demographics according to participant group.....	78
Table 4. Eighty-five items within their six clusters and the average ratings for each item's importance to the patient-navigator relationship.....	82
Table 5. Demographics according to participant group.....	103
Table 6. Stakeholder perspectives of each of the six components of interpersonal communication in breast cancer care patient navigation.....	105

LIST OF FIGURES

Figure 1. Investigator-developed conceptual model for patient navigation in breast cancer care....	4
Figure 2. Concept mapping process.....	24
Figure 3. Six-cluster concept map.....	79
Figure 4. Pattern match of the average rating for the importance of each cluster to the patient-navigator relationship across groups.....	87
Figure 5. Diagrams of relationships between six clusters and patient-navigator relationship....	112

PREFACE

This study was supported through funding from the Robert Wood Johnson Foundation Future of Nursing Scholars, the American Cancer Society Doctoral Scholarship in Cancer Nursing (130693-DSCN-17-081-01-SCN) and the University of Pittsburgh School of Nursing Swigart/Gold Doctoral Award for Scholarship in Nursing Ethics. Thank you to my dissertation chair Dr. Margaret Rosenzweig and my committee members Drs. Jessica Burke, Jill Demirci, Marci Nilsen, Catherine Bender and the late Susan Cohen for their guidance and support. I would like to acknowledge the time and dedication of the patients, patient navigators and administrators who participated in my study. I hope through this research I can honor your stories and your desire to help future patients with breast cancer. Finally, I would like to thank my husband, family, friends and colleagues for their encouragement and support along this journey.

1.0 PROPOSAL INTRODUCTION

Each year, over 200,000 women in the United States are diagnosed with breast cancer and advances in breast cancer treatment and care continue to improve their outcomes and survival. Despite these advances, health disparities persist among underserved communities in the screening, diagnosis, treatment and care of breast cancer. To address disparities in cancer care, patient navigator programs were developed with a central aim to help patients address barriers to care and navigate the complex healthcare system. Patient navigation is assistance by a non-medically or medically trained individual who assists patients in identifying and addressing individual and system level barriers to prevent attrition and promote patients' progression along the breast cancer care continuum.

Patient navigation is frequently cited as a tool for mitigation of breast cancer care disparity, with interpersonal communication identified as a key competency. Although integral to patient navigation, there is no established evidence defining this critically important construct in patient navigation. More broadly, interpersonal communication in health care is a dynamic, dialogic patient-provider interaction, rooted in the larger social context, with a goal of understanding patient concerns, explaining health issues, and engaging in shared decision-making. In order for patient navigation to be an evidence-based intervention, we need to identify the key components of interpersonal communication in breast cancer care patient navigation. This study proposes utilizing concept mapping, a community-based participatory research (CBPR) approach, to

facilitate the exploration of ideas and concepts surrounding interpersonal communication in patient navigation.

1.1 SPECIFIC AIMS

Therefore, the primary aims of this dissertation study are structured to reflect the major components of the concept mapping process and include:

1. Identify key interpersonal communication skills of patient navigators that patients, patient navigators and patient navigator administrators perceive to impact the patient-navigator relationship.
2. Prioritize the identified interpersonal communication skills of the patient navigator and explore the relative importance of each skill across groups (patients, patient navigators, administrators).
3. Understand and illustrate the pathways linking identified interpersonal communication skills to the patient-navigator relationship.

1.2 BACKGROUND AND SIGNIFICANCE

1.2.1 Health disparity in breast cancer care

Despite many advances in breast cancer treatment and care, disparity still exists across the breast cancer care continuum among underserved and minority populations. This disparity is evidenced

through 5-year breast cancer survival rates demonstrating that black women have the lowest 5 years survival rate of any racial or ethnic group (American Cancer Society (ACS), 2015). Currently the 5-year survival rate is 81% for black women and 92% for white women (ACS, 2015).

The survival disparity among racial and ethnic groups reflects a combination of barriers to care and important determinants of health, including poverty, less education, lack of health insurance and living in lower income areas (Halpern, Bian, Ward, Schrag, & Chen, 2007; Harper et al., 2009; Shi et al., 2015; Sprague, Trentham-Dietz & Gangon, 2011). Barriers to care exist at multiple levels: the patient, healthcare provider, health system and the larger social context. Barriers can include access to screening and treatment for cancer, adherence to treatment, co-morbidities, stage at diagnosis, level of knowledge about cancer screening and treatment, mistrust of the medical system, socioeconomic status and many other factors (Katz et al., 2014; Meredith, 2013; Tejeda et al., 2013). Unfortunately, as advances in breast cancer screening, diagnosis, and treatment improves cancer outcomes, the racial and ethnic disparities persist (Freeman, Muth & Kerner, 1995; Meredith, 2013; Whitman, Ansell, Orsi & Francois, 2011).

1.2.2 Patient Navigation Development

In an effort to address such disparities in breast cancer outcomes, patient navigation programs were developed in the 1990s by Harold Freeman in Harlem, New York City. These programs developed lay navigators to help low-income and medically underserved patients address identified barriers as they attempted to navigate the complex health system (Freeman et al., 1995; Freeman & Rodriguez, 2011; Vargas, Ryan, Jackson & Freeman, 2008). The program was designed to increase access to screening and early diagnosis of cancer among the underserved patients by focusing on outreach, education, advocacy and increasing access to social services (Freeman et al., 1995;

Freeman, 2013; Freeman & Rodriguez, 2011). The programs utilized lay navigators, persons who were culturally similar to the patients they served (Vargas et al., 2008). Patient navigators may be laypersons or community health workers, nurses, or social workers who vary in background and education level. While there is not a well-developed conceptual framework guiding patient navigation, Figure 1 depicts the investigator-derived conceptual model used to inform this dissertation proposal and discussion in the subsequent sections. The highlighted components of the model indicate the variables of interest guiding this dissertation study.

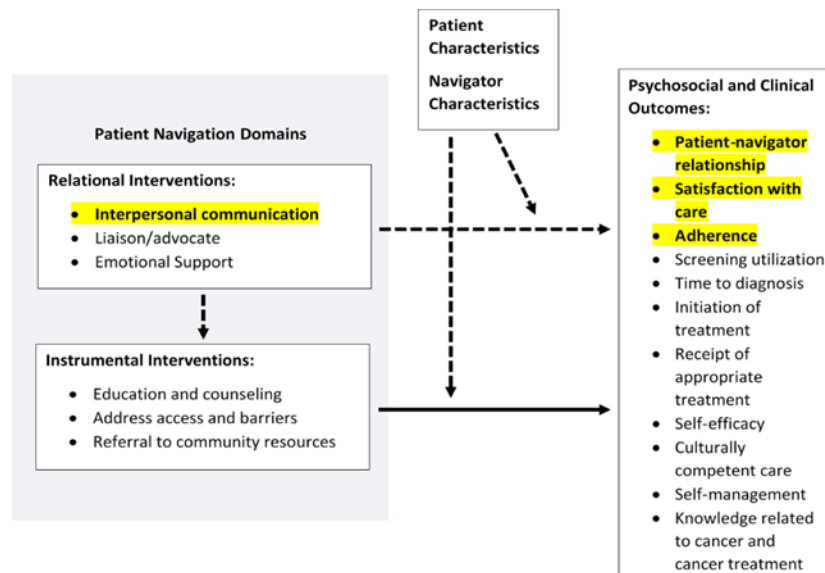


Figure 1. Investigator-Developed Conceptual Model for Patient Navigation in Breast Cancer Care

As these programs developed, patient navigation became defined as “assistance by an individual, either lay or medically trained, who assists patients in identifying and addressing individual and system level barriers to prevent attrition from and promote the patient's progression

along the cancer care continuum” (Freeman et al., 1995; Jean-Pierre et al., 2011; Meredith, 2013; Vargas, Ryan, Jackson & Freeman, 2008).

1.2.3 Logistical interventions and outcomes of patient navigation

Patient navigation programs in breast cancer demonstrate improvement in breast cancer care outcomes and the ability of patient navigation programs to address health care disparities across a variety of clinical contexts, with the greatest benefit shown among at risk populations (Battaglia et al., 2012; Dudley et al., 2012; Freund et al., 2014; Hunt et al., 2015; Kim et al., 2015; Lee et al., 2013; Markossian et al., 2012; Marshall et al., 2015; Mason et al., 2013; Oppong et al., 2016; Percac-Lima et al., 2013; Ramirez et al., 2014; Shroff et al., 2014; Simon et al., 2015). These improved outcomes include increased utilization of mammograms, reduction in time to diagnosis and initiation of treatment, as well as improved satisfaction with cancer care. Many of the patient navigation interventions are similar. They are delivered in-person or over the phone and focus on overcoming patient and system level barriers through education, appointment scheduling, reminders, emotional support, transportation, insurance, interpretation services, and physical accompaniment to appointments.

Patient navigation’s gain in popularity and subsequent widespread rapid adoption leaves many components of navigation poorly defined (Robinson-White et al., 2010). A review of breast cancer patient navigation studies recognized the narrow focus of navigation on the logistical-based or task-oriented interventions, of patient navigators, such as scheduling appointments and providing education (Haideri & Moormeir, 2011; Mason et al., 2013; Oppong et al., 2016). While the tasks of patient navigation are important to define, these reviewed studies did not describe or

evaluate the mechanistic process that allows the successful completion of the specific tasks facilitating the patient's progress as they move along the breast cancer care continuum.

1.2.4 Relational components of patient navigation

The process of exploring the relationship-oriented aspects of patient navigation has begun. These investigations, through qualitative studies with patients and patient navigators, have started to delineate the specific characteristics of patient navigators and interventions used by patient navigators that promote positive cancer care outcomes (Jean-Pierre et al., 2011; Phillips et al., 2014; Rousseau et al., 2014; Yosha et al., 2011). Additionally, these investigations have started to uncover and explore an additional layer to patient navigation interventions by looking at the relational dimensions of patient navigation which are much less concrete and more difficult to define (Cohen et al., 2013). Both navigators and patients have identified the importance of relationship building tasks, which include spending time with the patient, building trust, encouragement, social support, supporting autonomy, providing comfort, effective communication and coaching (Jean-Pierre et al., 2011; Phillips et al., 2014; Rousseau et al., 2014; Yosha et al., 2011). Furthermore, relationship building tasks may be more influential than instrumental interventions in promoting positive cancer care outcomes (Jean-Pierre et al., 2011; Phillips et al., 2014; Rousseau et al., 2014; Yosha et al., 2011).

1.2.5 Patient-navigator relationship

The patient-navigator relationship is a key outcome of patient navigation in breast cancer care (Fiscella et al., 2011; Pratt-Chapman et al., 2014; Oncology Nursing Society, 2017). Furthermore,

experts in patient navigation have also identified the importance of interpersonal communication skills of the patient navigator and their potential influence on the patient-navigator relationship.

Nevertheless, this relationship has gone largely unexplored in the scientific literature. The patient-navigator relationship potentially enables all other instrumental functions by allowing patient navigators to “break through” and learn about individual patient barriers that may not have been otherwise readily apparent (Jean-Pierre et al., 2011; Phillips et al., 2014; Yosha et al., 2011). Thus, the patient navigator’s ability to build trust, develop rapport, provide psychosocial support may be influential in building this relationship (Jean-Pierre et al., 2011).

Interpersonal Communication as a Key Competency of Patient Navigation

In recent years, national patient navigation leaders have identified key competency domains for patient navigators, including communication and interpersonal skills (Bail et al., 2016; Pratt-Chapman et al., 2014; Oncology Nursing Society, 2017). Furthermore, in a recent nurse navigator role delineation study by the Oncology Nursing Society, participants identified communication as a key task for oncology navigators. Consequently, improving communication with patients was noted as a need for professional development for oncology navigators (Lubejko et al., 2016). The focus on interpersonal communication is further supported by the patient-centered communication framework as well as the social-ecological model for addressing population health, which identify the interpersonal aspect of care as one of the primary contexts for improving patient-provider encounters and communication (Cohen et al., 2013; Epstein & Street, 2007).

Communication skills require further examination. Although interpersonal communication skills are identified as core competencies for patient navigators, the particular interpersonal components of communication skills that influence the ability of patients to overcome barriers to

care is understudied. Furthermore, the concept of interpersonal communication has not been clearly articulated in the patient navigation literature.

1.2.6 Interpersonal communication in patient navigation

Commonly, interpersonal communication in the healthcare professions is the ability of the provider to elicit and understand patient concerns, to explain healthcare issues and to engage in shared decision-making (Beaulieu et al., 2011; Roter & Larson, 2001). The theoretical and conceptual underpinnings of interpersonal communication can be drawn from many other disciplines including sociology, ethics, psychology and philosophy. In social psychology, communication at the interpersonal level encompasses the ability of the participants to simultaneously affect one another (Krauss & Fussell, 1996). A philosophical perspective on interpersonal communication emphasizes the notion of human existence as an encounter with others and the world; and dialogue, or language-oriented communication, is one way of expressing the interpersonal nature of human existence (Zank & Braiterman, 2014). Similarly, from an ethics perspective, in order to sustain and nurture dialogic interactions, both participants must be considered worthy of respect and allowed to express their own points of view.

Critical perspectives can challenge our view of interpersonal communication between patients and providers. Instead of the more traditional perspective where the patient is the receiver of the message from a more powerful, knowledgeable informer, patients can be seen as active interpreters, managers and creators of the meaning of their health and illness (Vanderford, Jenks & Sharf, 1997). The critical health communication praxis perspective promotes moving away from the self-serving discourse and paternalistic exercise of the medical encounter, where messages of health care providers are privileged over the health beliefs of the patient, those not in authority

(Lupton, 1994). From a feminist perspective, there is a greater emphasis on the influence of gender on relationships and interpersonal communication, which are informed by patriarchal histories, and subject to cultural and institutional inequalities (Manning & Denker, 2015). Through the incorporation of alternative and critical perspectives, we are able to develop a more comprehensive definition of interpersonal communication in health care. We can develop the definition as a dynamic, dialogic patient, provider interaction. This interaction is rooted in the larger social context, with a goal of understanding patient concerns, discussing health issues, and engaging in shared decision-making.

Therefore, patient navigation has both the opportunity and the challenge of prioritizing the voices of underrepresented groups as navigation continues to develop and conceptualize interpersonal communication. In order to advance the science of patient navigation and further our understanding of interpersonal communication, it will be extremely important to utilize research methods, such as community-engaged research methods, that promote the inclusion of marginalized groups, incorporate the knowledge and experience of key stakeholders, and utilize a collaborative approach to produce more meaningful and sustainable outcomes.

1.2.7 Community-engaged approach

Recognition of the inequities in health status associated with breast cancer care, as well as acknowledging the important role of patient navigation to address barriers to care, calls for a research approach that recognizes that researchers, providers and patients are shaped by the social, political and economic systems in which they work. Critical perspectives, such as feminist or critical race theory, question the objectivity of the research process noting that findings are mediated by values, scientific knowledge is a social creation, and the importance of dialogue

between the researcher and the participants (Campbell & Bunting, 1991; Ford & Airhihenbuwa, 2010; Henderson, 1995; Thomas et al., 2011). These are some of the key characteristics of community-engaged research, which emphasizes the important role of community members and stakeholders in the creation of scientific knowledge and their active engagement throughout the research process (Hatch et al., 1993; Israel et al., 1998). Community-engaged research not only aims to improve the health status of the communities and stakeholders involved, but also aims to provide participants more control and power in the research process (Hatch et al., 1993; Israel et al., 1998). Through this inclusive and collaborative research process, community partners and stakeholders are able to contribute their unique strengths and knowledge (Israel et al., 1998).

Community Based Participatory Research (CBPR), a community-engaged approach, has been identified as an important method for addressing health disparities and increasing the use of scientific evidence in communities (Hacker, 2013). Involvement of community partners allows for a shared ownership between the community and researchers strengthening the community's view of research, facilitating a deeper and more informed understanding of the research question and informing our research processes (Hacker, 2013; Israel et al., 1998). These key characteristics make CBPR an important approach for further exploration of the patient-navigator relationship and key interpersonal communication skills.

Concept mapping is an innovative, CBPR method which involves a mixed method approach that facilitates exploring the relationships of ideas and concepts. This structured process allows for the development of group consensus around a construct of interest (Burke et al., 2005; Vaughn et al., 2017). A specific strength of the concept mapping approach is that participants are very active throughout the research process from data generation to ensuring that the final results accurately represent the perspectives of participants versus that of the researcher (Burke et al.,

2005). It is a particularly appropriate method for gaining insights into how communities view and prioritize health topics. In a systematic review by Vaughn et al. (2017), the authors found concept mapping, when used as a community-engaged method, was able to promote the inclusion of a broad range of stakeholder perspectives throughout the research process. Inclusion of community stakeholders throughout the concept mapping process allows for the identification and delineation of key contextual and cultural nuances of the community that can inform and influence the impact of research outcomes and interventions (Vaughn et al., 2017). The resulting research outcomes and interventions are in turn more sustainable and applicable to the community.

This is a particularly appropriate method to examine interpersonal communication in patient navigation because it acknowledges the variation in stakeholder schedules and geographic locations. The online method of concept mapping allows participants to complete tasks according to their own time schedules as well as providing opportunities to save their work and return to it later. Furthermore, the structured steps, including both online and in-person sessions, allow for participants to contribute in different ways, through both individual and group discussion.

1.3 INNOVATION

The proposed study seeks to expand and challenge our current understanding of interpersonal communication in patient navigation. To our knowledge this proposed study will be the first to:

- a. Specifically examine interpersonal communication in breast cancer care navigation, with the potential to inform training programs for patient navigators.
- b. Utilize a community-engaged approach, where a variety of stakeholders, specifically patients, play a key role in the data generation, analysis, interpretation and dissemination, to

examine interpersonal communication in patient navigation. Potentially establishing a framework for future investigations to identify and define the important elements of patient navigation.

c. Examine patient navigation through concept mapping, a mixed-method design which applies quantitative analyses to qualitative data and produces visual representations of the participant perceptions.

1.4 PRELIMINARY STUDIES

To gain a better understanding of the experiences of women with breast cancer as well as the developing role of patient navigation in breast cancer care, the principal investigator conducted or participated in several preliminary studies. The pilot work described in this section provided exposure to the unique needs of this proposed study's population of interest as well as opportunities to engage with oncology researchers and experts in patient navigation.

1.4.1 Evidence to support the need for further clarification of the patient navigator role.

To inform the development of the conceptual framework guiding this dissertation study, an integrative review was conducted by the PI to provide an evaluation of the impact of breast cancer patient navigation programs over the last 5 years from 2011 to 2016. Outcomes that were evaluated were: 1) timeliness of care, 2) the characteristics of patient navigators and 3) patient navigation training.

For the purposes of this review, timeliness of care was defined as the timely movement of patients across the breast cancer care continuum. Timeliness of care is a quality care indicator and

a fundamental patient-centered outcome of patient navigation (Basu et al. 2013, Fiscella et al., 2011; National Consortium of Breast Centers (NCBC), n.d.). Currently, there is no gold standard for the measurement of timeliness of care and to date no study has compared the different methods of measuring timeliness of care utilized in patient navigation research.

This study reviewed published articles in PubMed and CINAHL through searching MeSH (Medical Subject Headings) terms as well as title and abstract for the following keywords: “breast neoplasm”, “mammography”, “breast cancer”, “breast tumor”, “mammary carcinoma”, “breast health”, “patient navigation”, “care navigation”, “lay navigation” and “nurse navigation”. To be included studies were English-language articles published from January 2011 through the July 2016 which provided data on (1) timeliness of care as a result of breast cancer patient navigation at any stage of the breast cancer care continuum and (2) whether navigation was conducted by a non-medically trained person, lay patient navigator, or a trained medical person, such as a nurse navigator. Only published articles in peer-reviewed journals were included.

After application of the inclusion criteria, 20 articles were included in the final analysis. Overall, the studies found positive outcomes on timeliness of care. Only three studies (15%) had non-significant findings. Patient navigation programs did improve timeliness of breast cancer care outcomes among vulnerable populations, particularly those individuals at higher risk for delays or increased barriers to care. Accurate comparisons across studies were hampered by the absence of standard measurements of timeliness of care. For example, Koh et al. (2011) measured time from biopsy to treatment initiation and time from biopsy to initial consultation while Ramirez et al. (2014) measured time from definitive diagnosis to treatment initiation. Furthermore, timeliness was measured in average days to completion, percentage of population reaching the key event, or completion within a certain time period, such as 30 days, 60 days or 365 days (Basu et al., 2013;

Dudley et al., 2012; Haideri & Moormeier, 2011; Kim et al., 2015; Percac-Lima, Ashburner, McCarthy, Piawah, & Atlas, 2015; Ramirez et al., 2014).

The measurement of timeliness of care did not extend across the breast cancer care continuum, with 70% of the included studies only evaluating screening utilization rates (35%, n=7) or diagnostic resolution (35%, n = 7) (Battaglia et al., 2012; Braun et al., 2015; Drake et al., 2015; Dudley et al., 2012; Hoffman et al.; 2012; Hunt et al., 2015; Lee et al., 2013; Markossian et al., 2012; Marshall et al., 2015; Mason et al., 2013; Oppong et al., 2016; Percac-Lima et al., 2013; Shroff et al., 2014; Simon et al., 2015). Measurement of time to surgery, chemotherapy, medical oncology and/or radiation therapy as well as survivorship visits was not included. The improved timeliness of care outcomes showed increased utilization of mammography, faster time to follow-up, and decrease in time to definitive diagnosis and treatment initiation with small to medium effect sizes (Battaglia et al., 2012; Dudley et al., 2012; Hoffman et al.; 2012; Kim et al., 2015; Koh et al., 2011; Mason, 2001; Ramirez et al., 2014; Shroff et al., 2014).

Additionally, included studies were limited by lack of description of the patient navigation intervention including the characteristics of the patient navigators, the navigation protocol, or their specific skills or the training received. Common characteristics did arise among the patient navigation interventions including focus on care coordination, providing education and outreach, scheduling appointments, providing reminders, assisting with transportation, addressing financial needs, providing interpretation services and referral to community resources. No discussion or evaluation was provided related to the relationship-oriented tasks of patient navigators, such as providing emotional support, interpersonal communication or accompaniment. Additionally, no discussion of specific skills utilized by patient navigators to promote positive cancer care outcomes was provided.

Patient navigator characteristics and training were not discussed in depth, seven out of 20 (35%) did not describe the patient navigator training and three (15%) did not provide patient navigator characteristics (Basu et al., 2013; Drake et al., 2015; Haideri & Moormeier, 2011; Kim et al., 2015; Koh et al., 2011; Lee et al., 2013; Oppong et al., 2016). Sixty percent of the included patient navigator programs employed navigators from the community who were culturally and/or linguistically concordant with the patient population. Other programs utilized trained medical professionals, such as oncology nurses or social workers (Basu et al., 2013; Dudley et al., 2012; Hoffman et al., 2012; Koh et al., 2011). Minimal education was required for lay patient navigators, generally a high school diploma or experience working in the community. Patient navigator training also varied from study to study. If training was described, it typically included a combination of didactic learning, shadowing, mentoring, basic breast cancer education, or care coordination training.

Even though there are positive benefits shown from the reviewed patient navigation programs, there still does not seem to be clear best practices for patient navigation interventions, nor does there seem to be an established training or clearly defined role of the patient navigator. The literature is limited to early stage navigation and does not truly encompass the breadth of the breast cancer care trajectory. The literature also points to the need for standardization of outcomes of patient navigation, such as timeliness of care. Furthermore, there is no identification or evaluation of the relationship-oriented tasks of patient navigation, such as interpersonal communication, and their potential influence on cancer care outcomes.

1.4.2 Evidence for the role of the patient-navigator relationship

The Adherence, Communication, Treatment, and Support (ACTS) randomized controlled intervention study was a one-time psychoeducational intervention encouraging adherence of African American women to prescribed chemotherapy. The study staff and interventionist were African American. The usual care arm received standard patient education regarding recommended chemotherapy. Surprisingly, as compared to previous rates of chemotherapy adherence in that medical oncology clinic between 60-70% for Black women, 98% of both the intervention and usual care groups initiated chemotherapy. Nonspecific factors are variables that may influence study results through the formation of a relationship between the participants and interventionist and may have influenced the ACTS results. The relationship that forms may be influenced by similar life experiences, interventionist qualities (e.g. warmth, positive regard, competence) and attention bestowed on the participant. Therefore, this preliminary study was a secondary analysis of the ACTS intervention study. The PI aimed to explore the influence of nonspecific factors of a largely racially concordant study team on study outcomes in the usual care group and compare the results with previously obtained debriefing questionnaire data from the ACTS intervention group. This preliminary study's results were published in the Journal of Oncology Navigation and Survivorship, see Appendix A.

To evaluate non-specific factors, an investigator-derived debriefing questionnaire was completed in both groups regarding nonspecific factors such as support, bond, and concern displayed by the ACTS study team or the interventionist and whether those factors influenced their follow-through with chemotherapy, level of support felt, and distress level. Descriptive statistics and independent t tests were used to analyze subscores and compare total scores of both groups.

Study findings showed that concern for health and well-being ($n = 32$, $M = 11.4$ out of 15 in usual care; $n = 50$, $M = 11.0$ in intervention) and support ($M = 11.4$ in usual care out of 15, $M = 10.7$ in intervention) were ranked highest in both groups. While the usual care group had higher mean scores overall, the mean subscores and total score ($P = .4$) between the groups were not significantly different.

Therefore, regardless of intervention, all women felt a sense of support. These elements of support, concern for health and well-being and the bond developed with study staff may have encouraged adherence, providing a foundation for the focus on relational components of patient navigation in this study. The results from this study also point to the potential influence of the patient-navigator relationship and the need to better understand the interpersonal communication skills used to build and sustain that relationship.

1.4.3 Evidence to support potential role of patient navigation in addressing economic hardship

Patients with advanced cancer experience significant financial distress. Thus, the PI and her dissertation study chair conducted a cross-sectional, comparative, descriptive study of 100 patients with advanced cancer in outpatient medical oncology clinics in Western Pennsylvania. This study was published in the Journal of Community and Supportive Oncology, see Appendix B. Study variables included symptom severity (McCorkle Symptom Distress Scale), quality of life (FACT-G plus Spiritual Well-Being Short Form), perceived financial hardship (Psychological Sense of Economic Hardship Scale), and overall cancer-related distress (NCCN Distress Thermometer) (Jacobsen et al., 2005; Ransom, Jacobsen & Booth-Jones, 2006; Vodermaier, Linden & Siu, 2009;

McCorkle & Quint-Benoliel, 1983; Cella et al., 1993; Peterman et al., 2002; Barrera, Caples & Tein, 2001).

Perceived financial hardship was mildly correlated with overall cancer-related distress (r , 0.409; $P < .001$), symptom distress (r , 0.409; $P < .001$), and overall quality of life scores (r , 0.323; $P < .001$). In addition, patients experiencing higher levels of perceived financial hardship experienced worse quality of life overall ($P = .002$), higher levels of cancer-related distress ($P < .001$), and worse symptom distress ($P < .001$). These results, similar to the broader cancer literature, show the importance of both assessing financial hardship among patients with cancer as well as the need for cost discussions between health care providers and patients to pragmatically address the financial burden of cancer care (Zafar et al., 2015; Kent et al., 2013; Chino et al., 2014).

Providers, such as patient navigators, have been identified as effective in assisting patients with financial planning and accessing community resources to address financial burden and assistance (Mcdougall et al., 2014). Interpersonal communication may play a key role in the ability of patient navigators to both assess financial hardship and participate in cost discussions with patients. Thus, supporting the need to expand our knowledge surrounding the interpersonal communication skills that promote positive cancer care outcomes.

1.4.4 Stakeholder engagement plan

CBPR is an important approach for addressing health disparities and increasing the use of scientific evidence in communities and is the method being utilized to explore interpersonal communication in breast cancer patient navigation in the proposed dissertation study. Furthermore, CBPR and concept mapping call for the active participation of participants through all parts of the research process, from planning the research to ensuring that the final results accurately represent the

perspectives of participants versus that of the researcher. Therefore, this study's objective is to engage stakeholders familiar with patient navigation in breast cancer care to inform the development and planning of the dissertation proposal.

This study utilized a qualitative design where identified stakeholders/participants (patients, patient navigators and patient navigator administrators) participated in semi-structured interviews. The semi-structured interviews focused on whether the research question and focus of the dissertation study are relevant to key stakeholders' experiences with patient navigation, assessed the concept mapping focus prompt for clarity and usability, and gathered input on appropriate recruitment and retention strategies for the proposed dissertation study.

Six thirty-minute interviews were conducted with three patients with breast cancer, two breast cancer patient navigators and a patient navigator administrator. Once transcribed, the interview data will be coded and analyzed for emerging themes. Transcription and data analysis are ongoing.

1.5 RESEARCH DESIGN AND METHODS

1.5.1 Design

This study will utilize concept mapping through a mixed method approach. Concept mapping uses a community based participatory approach to collect qualitative data. The process then uses quantitative analyses to produce visual representations of the themes representing the qualitative data (Albert & Burke, 2014; Kane & Trochim, 2007). Concept mapping was developed in the 1970s as a strategy for examining factors that influence how students learn, noting that individuals

learn around themes that are part of their cultural environment and those concepts can be organized and represented through concept maps (Novak & Cañas, 2006). In the 1980s, concept mapping was adapted for use in program planning and evaluation (Trochim, 1989). In 2005, concept mapping was introduced as a participatory method for public health researchers with a goal of helping community health researchers to capture the lived experiences of community members (Burke et al., 2005).

1.5.2 Setting

The study will be conducted at three (UPMC Magee, UPMC Altoona, Meadville Medical Center?) cancer centers in Western Pennsylvania. These cancer centers have strong patient navigation programs in breast cancer care and represent distinct areas of Western Pennsylvania, both rural and urban. Collaboration with three cancer centers from across Western Pennsylvania will allow for a broader sampling of participants, locations within the area, and health systems. The study will be conducted from August 2017 to June 2018.

1.5.3 Population

This study seeks to involve a variety of stakeholders or participants key to patient navigation in breast cancer care. Involvement of community partners allows for a shared ownership between the community and researchers which can improve the community's view of research, facilitate a deeper and more informed understanding of the research question and inform our research processes (Hacker, 2013; Israel et al, 1998). In the proposed study, there are several key stakeholders that have been identified as essential to the research process including patient

navigators, patients, and patient navigator administrators (Lubjeko et al., 2016). While there are potentially other stakeholders, the exploratory aim of this study will limit the stakeholders to these three identified groups. Patient navigators as well as patients play a key role in the communication process. Patients with breast cancer utilizing patient navigators can represent an array of age groups, cultures, educational backgrounds, income levels, knowledge about breast cancer and cancer treatment as well as geographic regions, both rural and urban communities in Western Pennsylvania.

Patient navigators may be either clinically-licensed (e.g. nurse or social worker) or lay persons representing a broad age range and experience in oncology care (Lubjeko et al., 2016). Most are newer to their role or are still developing their role within the healthcare team and have received very little to no training in patient navigation. Furthermore, the breast cancer patient navigator role is heavily dominated by white females (Lubjeko et al., 2016).

Patient navigator administrators play a large part in the hiring, training and support of patient navigators in cancer care. Similar to patient navigators, administrators may also be either clinical (e.g. physician or nurse) or non-clinical (e.g. program director) with a broad range of experience with patient navigation. These administrators typically do not have certification in patient navigation, but may be experienced in breast cancer care or patient navigation. Moreover, each stakeholder group, as well as the individuals, bring their own needs, understanding of the world, values, principles, qualities and skills that are fundamental to the interpersonal context of communication (Hall, Chapman & Lee, 2015).

1.5.4 Sample

This study's sample will focus on the previously mentioned key stakeholder groups in Western Pennsylvania including: patients who receive or have received breast cancer patient navigation services, different types of breast cancer patient navigators (i.e. nurses, lay, social worker), and patient navigator supervisors and administrators (Lubjeko et al., 2016; Pratt-Chapman et al., 2015). Previous concept mapping studies samples ranged from 10 to 40 participants (Albert & Burke, 2014; Burke et al., 2005; Kane & Trochim, 2007; O'Campo et al., 2005; Trochim et al., 2004). This sample size range provides a reliable framework that facilitates a variety of opinions and good group discussion and interpretation (Kane & Trochim, 2007). However, as concept mapping also involves applying quantitative analyses to qualitative data, the study sample will also need to include sufficient numbers of participants from each stakeholder group in order to make accurate comparisons across groups. This study will obtain 10-15 participants for each stakeholder group.

1.5.5 Sampling Procedures

Guided by the principles put forth by Kemper and colleagues (2003) this study's sampling strategy involved recruitment of individuals who would contribute knowledge to the understanding of interpersonal communication in breast cancer patient navigation, and have demonstrated the ability to draw clear inferences and provide credible explanations. Furthermore, this study sought to incorporate a sampling strategy that is ethical, feasible and efficient (Kemper et al., 2003). Concept mapping is a hypothesis-generating approach with a goal of achieving a broad sampling of ideas to ensure the inclusion of a wide variety of viewpoints, develop additional information for data analyses, as well as promoting a larger "buy in" to support the resulting framework (Kane &

Trochim, 2007). Thus, this study utilized purposive sampling to provide heterogeneity (Kane & Trochim, 2007). Purposive sampling is a sampling strategy commonly used in qualitative and mixed method research for the identification and selection of information-rich participants (Patton, 2002). This sampling strategy involves identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with the phenomenon of interest, interpersonal communication in breast cancer patient navigation (Creswell & Plano Clark, 2011). Patton (2002) suggests that purposeful samples can be further stratified by selecting cases that vary according to a key dimension. For this study, a stratified purposeful sample was employed by stratifying by the three identified stakeholder groups: patients, patient navigators and patient navigator administrators. The use of stratified purposively sampling seeks to provide an understanding of variation and common elements within the population of interest (Patton, 2002).

Following IRB study approval, study participants were recruited from a variety of patient navigator networks in Western Pennsylvania, including cancer centers (i.e. Magee, Altoona, Meadville Medical Center) and the Pennsylvania Patient Navigation Network. Participant recruitment took place during the first three months of the study. Potential patient participants were working with a patient navigator in breast cancer care at any point in the cancer care continuum and had communicated with their navigator within the last three months. These criteria were selected to reduce recall bias. Individuals were identified by a patient navigator at one of the three cancer centers, who asked the patient if they were willing to speak to the researcher about a patient navigator study. The patient navigator provided the PI with the individuals' contact information. Participants were informed of the opportunity to participate in the study either in-person, by telephone, or e-mail, according to their preference. Then the PI introduced the study, answered any questions and obtained informed consent.

Patient navigators must have been working in breast cancer care navigation and could be either medically or non-medically trained navigators (i.e. nurse, social worker, lay). Patient navigator administrators were either supervisors or coordinators of breast cancer care navigation. Patient navigators and administrators were informed of the opportunity to participate through email outreach efforts utilizing the Pennsylvania Patient Navigation Network listserv and could come from other health centers outside of the three cancer centers utilized for patient recruitment. For all participant subgroups, inclusion criteria included: must be 21 years or older, read and write the English language, and have the time and availability to participate in the concept mapping sessions.

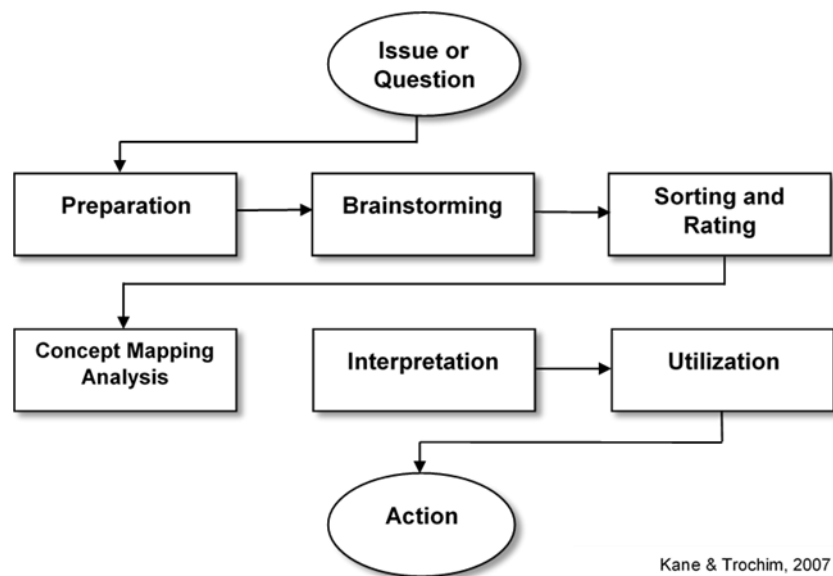


Figure 2. Concept Mapping Process

The structured concept mapping process involves six main steps, illustrated in Figure 2. Progression through each step allows for ongoing data collection and analysis with study aims being addressed at specific steps in the concept mapping process, see Table 1.

Table 1. Concept mapping activities and associated study aim

Study Aims	Brainstorming	Sorting/Rating	Analysis	Interpretation
Aim 1	X			
Aim 2		X	X	
Aim 3			X	X

1.5.6 Data Collection

The data collection occurred during three steps in the concept mapping process, brainstorming, sorting and rating, utilizing remote input through the Concept System Software. The Concept System Software was specifically designed to conduct all the analyses in the concept mapping process as well as subsequent analyses, such as evaluating differences between subgroups (Trochim, 1989; Burke & Albert, 2012; Kane & Trochim, Concept Systems Incorporated, 2016). The software is user-friendly and allows the researcher to conduct analyses in real-time. The Concept Systems Global Max software allows all data collection to be conducted online (Burke & Albert, 2012; Concept Systems Incorporated, 2016). For those participants that did not have regular or reliable access to the internet, alternative routes of participation during the online data collection were offered, including mail or in-person data collection options.

Through the online data collection, each participant asynchronously participated in the brainstorming step of the concept mapping process to record demographic data and generate ideas in response to the focus prompt. The brainstorming step occurred over a 3-month period. Initially, each participant, after informed consent, was supplied with a username and password for the online Concept System Global portal by email. After logging in, participants completed a brief demographic questionnaire including information related to age, race/ethnicity, education level, income, and exposure to patient navigation training. Then, the participants were taken to a main page with an active link to the first step in the concept mapping process, the generation of statements related to interpersonal components of patient navigation. During this step, participants were provided an initial introduction to the concept mapping process. Participants then had the opportunity to respond to the following focus prompt: “Generate statements that describe the interpersonal communication skills of the patient navigator that affect, both good and bad, the patient-navigator relationship”. Participants were encouraged to provide many phrases or sentences in response to the focus prompt. Once the initial email with the username and password was sent, participants had two weeks to complete the task. If the task was not completed after two weeks, then they received a reminder email. After three weeks if the task was not complete, the participant received an investigator-initiated phone call as a reminder and to assess for any barriers to completion. The resulting generated statements were combined into a master list of unique statements through idea synthesis (Kane & Trochim, 2007). The goal of idea synthesis is to produce a master list of unique ideas with each statement representing only one idea (Kane & Trochim, 2007). Furthermore, this step seeks to ensure that each statement is relevant to the concept mapping focus, consolidates conceptually similar or redundant statements to create a more manageable list for future steps, as well as ensures clarity of the statements for understanding by

all participants (Kane & Trochim, 2007). During this step, the master list was consolidated by the primary investigator and one dissertation committee member once all participants had completed the brainstorming step. Guided by content analysis, the two researchers consolidated the list through identifying keywords in the generated statements (Kane & Trochim, 2007). Additionally, compound ideas, a statement with two or more distinct ideas, were split into two separate statements (Kane & Trochim, 2007). Then final editing of statements was conducted to correct grammar or spelling, reword technical jargon and ensure that each participant could understand the meaning of the statement (Kane & Trochim, 2007). However, the goal was to retain all generated ideas and preserve the original meaning of each statement as best possible. To create a master list of statements that does not create unnecessary burden on participants, the list was limited to seventy-five statements or fewer. Furthermore, previously identified and relevant ideas from the scientific literature, including feminist and critical race theory perspectives, and preliminary studies were added to the consolidated list, if they had not already been identified through the brainstorming step.

The structuring step involved both sorting the individual statements and rating them and took place over a 2-month time frame. This step provided the necessary data for further concept analysis. These steps were also conducted asynchronously online through the Concept Systems Global online portal. During the sorting step, each participant sorted the statements based on their perceptions of similarity among the statements by grouping them into “piles”, or sets of like ideas (Kane & Trochim, 2007). The sorting step helps to identify the relationships among the different statements from the participant’s point of view (Kane & Trochim, 2007). Participants were also informed that they could not have individual piles for each statement, one pile with all items, or a mixed pile consisting of statements that did not belong with the other sorted piles (e.g.

miscellaneous) (Burke et al., 2005; Burke et al., 2009; O’Campo et al., 2005; Trochim et al., 2004).

During this step, the participant also assigned a title, or label, for each pile.

Then participants moved to the next task in the online portal to rate the statements. Participants responded to the provided rating prompts using a Likert type scale, see Table 2. Three outcomes were selected because the Concept System Software allows up to three rating scales. The outcomes of the patient-navigator relationship, adherence and patient satisfaction with cancer care are key patient reported outcomes of patient navigation as identified by leaders and experts in patient navigation (Fiscella et al., 2011; Oncology Nursing Society, 2017). A similar schedule was used for this step of data collection as well, where participants were given 2 weeks to complete the sorting and rating steps, then received a reminder email. If after 3 weeks the information was not complete, then they received a phone call reminder from the investigator.

Table 2. Description of rating scales and patient navigation outcomes

OUTCOME	RATING STATEMENT	VALUE INDICATOR
Patient-navigator relationship^{a,b}	Please rate on a scale of 1 to 5 the importance of each item to facilitating a positive relationship between the patient and the navigator: 1 = not important; 2 = somewhat important; 3 = moderately important; 4 = very important; 5 = extremely important	Degree of importance of each item to the patient-navigator relationship
Adherence^b	Please rate on a scale of 1 to 5 how each item is related to a person’s ability to follow-through with the treatment recommendations of the provider (e.g. mammogram, treatment initiation, follow-up care): 1 = no relationship; 2 = some relationship; 3 = moderate relationship; 4 = strong relationship; 5 = extremely strong relationship	Strength of perceived relationship between each item and adherence to provider’s recommendations
Satisfaction with care related care^b	Please rate on a scale of 1 to 5 how each item impacted satisfaction with the cancer care received: 1 = not at all; 2 = somewhat; 3 = moderately; 4 = strongly; 5 = extremely	Degree to which each item impacted satisfaction with cancer related care.

a. Oncology Nursing Society, 2017; b Fiscella et al., 2011

1.5.7 Analysis Plan

All the analyses of the sorting and rating data and map development were performed with the Concept Systems software (Concept Systems Incorporated, 2016). Utilizing the sort information logged by participants online through the Concept Systems Global portal, a series of analyses were conducted to produce maps for the conceptual domain (Kane & Trochim, 2007). Over the two months leading up to the final interpretation session, the investigator performed the core analyses.

First, a similarity matrix was produced that included the sort information for each participant. These pooled results produce an estimate of the similarity among statements across all the participant sort data (Burke et al., 2005, Trochim et al., 2005). The resulting combined group similarity matrix includes values for each statement ranging from zero to the total number of participants, with a high value indicating that more participants sorted a pair of statements together and that the statements are conceptually similar to another (Kane & Trochim, 2007).

Next, through nonmetric multidimensional scaling of the pooled similarity matrix, each statement was positioned as a point on a two-dimensional map, a point map, through an iterative process (Davison, 1983; Kane & Trochim, 2007; Kruskal & Wish, 1978). After the point map was created, the stress value was evaluated. The stress value is the primary diagnostic statistic for multidimensional scaling, which helps to determine if the two-dimensional map solution is an accurate data representation (Kane & Trochim, 2007). A lower stress value suggests a better representation of the original similarity matrix; the recommended cutoff is 0.365 (Kruskal & Wish, 1978).

Then, hierarchical cluster analysis divided the statement points on the map into clusters, or similar concepts. Utilizing Ward's algorithm, the sum of squares of the distance between statement points was minimized producing non-overlapping clusters (Burke et al., 2005; Everitt, 1980; Kane

& Trochim, 2007; Trochim et al., 2005). Cluster solutions may range from a single cluster including all statements to each statement in a cluster of its own (Burke et al., 2005; Everitt, 1980; Kane & Trochim, 2007; Trochim et al., 2005). Thus, several final cluster solutions may be produced. The final cluster solution is typically determined by the participants in the final group interpretation session.

Preliminary analyses were conducted in advance of the interpretation session to determine a more practical number of possible cluster solutions for participants to choose from, instead of the entire range of possible solutions. First, the investigator conducted a bridging and anchoring analysis. Anchor statements reflect greater group consensus on their similarity to adjacent statements on the map, where bridging statements reflect less group consensus with participants sorting the statement sometimes at distant points on the map (Kane & Trochim, 2007). While there is no set standard for selecting the final number of clusters, the investigator can narrow it down through the use of upper and lower limits based on what would be useable in the patient navigation context. From there, each cluster level was examined within that range with a focus on the merged clusters and whether it is better for them to combine or remain separate. This step was conducted by the primary investigator and a dissertation committee member. If agreement could not be reached, then a third researcher evaluated the cluster levels. At least two different cluster solutions were selected to take to the participants in the interpretation session with the final cluster solution being determined by the study participants (Kane & Trochim, 2007).

Subsequent preliminary group comparisons were conducted on statement ratings of importance across all the participants as well as by subgroups from the predetermined cluster maps. However, these may change after the final cluster solution is determined. Additionally, the group may wish to see additional comparisons with the statement rating data. Point rating maps were

produced to identify the average rating for each statement across all the participants as well as by subgroups. Additionally, cluster rating maps were produced to identify the average rating for all the statements within an individual cluster. Pattern matching displays were employed to compare average cluster ratings for importance between different subgroups to assess consensus between groups (Kane & Trochim, 2007). Furthermore, go-zone displays, bivariate graphs, were produced to provide additional within cluster detail, particularly to compare the ratings of individual statements between groups.

1.5.8 Interpretation

During the final interpretation session, interpretation of findings and development of the final concept map was conducted by the participants. Participants were provided with information for the final interpretation session by email or phone and sent at least one reminder before the meeting. These sessions took place as separate, live, in-person sessions lasting approximately 2 hours. Based on results of the first two aims, The PI and her dissertation committee examined the level of variation between the three stakeholder groups and determined whether the groups should be combined or separated for the final interpretation sessions to maintain participants' willingness and comfort in sharing their experiences. These sessions were audio-recorded and led by a facilitator, the primary investigator. An additional researcher was also present to take notes during the discussion. The in-person session allows for the stakeholders and researchers to interact as well as provides the opportunity for participants to see how their individual ideas have contributed to the research process (Kane & Trochim, 2007). Serving as the facilitator, the primary investigator began by providing an overview of the agenda for the session as well as providing a summary of the brainstormed ideas. The resulting point map and concept maps from the preliminary analyses

were presented and explained to the group. After finalizing the final concept map solution, the participants were asked to name the clusters, with examples from the labels provided by participants during the online sorting step. The final concept map with cluster names represents the main result of the concept mapping process. From there, the facilitator, engaged the participants in a general discussion about the final map as well as collaborated with the participants to identify major regions on the map (Kane & Trochim, 2007). Then the facilitator shared the point rating map, cluster rating map, pattern matching and go-zones produced during the preliminary analyses to discuss their relevance and implications (Kane & Trochim, 2007).

During the final session, in small groups, the participants diagramed how the statements within a cluster relate back to the focus statement (Albert & Burke, 2014). Additionally, in that final interpretation session, participants had input on future steps, including research questions, action steps and information dissemination (Albert & Burke, 2014; Burke et al., 2005). The PI sought to involve stakeholders in the dissemination of study results through fostering discussion among participants about the best ways to disseminate the information to other stakeholders, where to share the information and offer opportunities to participate in the dissemination of study results.

1.5.9 Rigor and Trustworthiness

This study utilized several strategies for promoting trustworthiness and providing accurate representations of the data collected. The structured stepwise approach of the concept mapping process provides support for the rigor of the study design and implementation. Furthermore, the concept mapping process promotes trustworthiness of the study results through several validation and member checking strategies including: study participants and groups generate the ideas, participants sort and rate the items on importance, seeks consensus among participants for clusters

and naming of clusters, participants decide how the concepts relate to one another and the overall research question, and participants help decide next steps and future research. An intercoder agreement process for reliability of the data was in place as we used more than one researcher to consolidate the idea statements into one master list and if consensus was not reached, a third researcher was brought in to review (Creswell, 2013). Lastly, reflection on the research process was also key to the reporting of this study's findings. The primary investigator not only participated in self-reflection and debriefing with members of her dissertation committee but also acknowledged her position as a student and researcher to the study participants and reported how her experiences may shape the study's findings, conclusions and interpretation (Creswell, 2013).

1.6 STUDY LIMITATIONS AND ALTERNATIVE APPROACHES

While there are many benefits to concept mapping, there are some potential limitations to discuss related to this process. While utilizing the online concept mapping process might make participating in the research more accessible, it might also limit our sample as it requires a certain level of computer literacy and reliable access to the internet. It may be necessary to provide other routes for participation if internet access creates a barrier to participation in the study, such as mailing responses. Additionally, using the online system may require extending the process to allow time for participants to complete the steps as well as require processes in place to send prompts and reminders to improve participant retention. Another limitation of the online design is the absence of group dynamics during the brainstorming session, since commonly participants may develop an idea based off another participant's response, such as during focus groups (Albert & Burke, 2014). Utilizing patient navigators to select potential patient participants may introduce

bias into the sampling and recruitment procedures. Furthermore, accurately combining the large number of brainstormed statements into a manageable but representative master list may also be challenging, as there can be duplication of ideas through the online brainstorming step.

1.7 HUMAN SUBJECTS

This study was reviewed and approval obtained by the Institutional Review Board at the University of Pittsburgh. Once individuals agreed to participate in the study, the principal investigator would approach the individuals to confirm eligibility, describe the study, answer questions and obtain informed consent. While this study has minimal risk, there is potential for psychological distress through participation in the several concept mapping steps as well as the potential for group or power dynamics, with a mixture of patients, providers and supervisors involved in the study. Ground rules were set for the in-person group session to promote open dialog among the participants. Additional risk includes the risk for breach of confidentiality with the participant data. To reduce the likelihood of a breach of confidentiality, demographic data and online recorded information, were stored on a password protected computer. Additionally, each participant was given a unique username and password to provide secure access the concept mapping website. The participant may experience fatigue associated with length of concept mapping steps, but every effort was made to provide proper support for the online software. The online system also allows for participants to save their progress and return later. Moreover, efforts were made to respect participant time during the in-person interpretation session, as well offering breaks. At the beginning of in-person sessions, participants were informed of steps being taken to maintain confidentiality. Participants did not receive direct benefit from participating in the study. Data and

safety monitoring were conducted regularly between the PI and her dissertation committee and any unanticipated adverse events were reported immediately to the IRB. This study is designed to enroll female participants who have received or are receiving breast cancer patient navigation; however, no participant were excluded based on their race or ethnicity. Furthermore, no children under the age of 21 were included in this study. Additionally, this study includes advisement from key stakeholders on the best methods to recruit and establish a study atmosphere that encourages participation of minority individuals. Furthermore, as potential participants could have a terminal illness, proper methods were employed to provide accurate information concerning eligibility for participation, clearly convey risks and benefits, and inform potential participants of any individual costs associated with participating in our research study.

1.8 RESEARCH PARTICIPANT RISK AND PROTECTION

1.8.1 Human Subject Involvement

Participants were women and men age 21 and older who had experience with patient navigation in breast cancer care either as a patient, a patient navigator or patient navigator administrator at three cancer centers in Western Pennsylvania. To be included, participants must be age 21 and older currently or have previously worked with a patient navigator, within the last 3 months, or as a patient navigator or administration in breast cancer care. Those individuals that do not speak the English language were excluded.

Inclusion of Women. With a specific focus on breast cancer patient navigation, this study focused on the recruitment of a sample whose gender distribution generally corresponded to the distribution of the breast cancer and patient navigator populations at the study sites.

Inclusion of Minorities. As patient navigation was developed to address barriers to care faced by minority and underserved communities, this study sought to represent racial and ethnic minorities in its sample. No one was excluded from participation in this study based on race or ethnicity.

Inclusion of Children. No children were included in this study; therefore, the age limit was set at age 21 years and above.

Sources of Materials. Data were obtained for the specific purposes of this study directly from the research participants through in-person group sessions and the online concept mapping software.

Potential risk and Protection Against Risks. There is minimal risk associated with participation in this study. There is potential for psychological distress through participation in the several concept mapping steps as well as the potential for group or power dynamics, with a mixture of patients, providers and supervisors involved in the study. Ground rules were set for the in-person group session to promote open dialog among the participants. Participants could experience fatigue as a result of participating in data collection online or in-person. The online data collection allows participants to save their work and return to it later. Moreover, efforts were made to respect participant time during the in-person interpretation session, as well offer breaks. Additional risk includes the risk for breach of confidentiality with the participant data. To reduce the likelihood of a breach of confidentiality, demographic data and online recorded information, will be stored on a password protected computer. Additionally, each participant was given a unique username and password to provide secure access to the concept mapping website. The principal investigator met with her dissertation committee and/or dissertation chair on a regular basis to review any issues

related to recruitment, maintenance of confidentiality, protection of participants, and conduct of the study. Any unanticipated events were reported to the University of Pittsburgh's Institutional Review Board (IRB), consistent with their guidelines.

Recruitment and Informed Consent. Participants were recruited from cancer centers in Western Pennsylvania and the Pennsylvania Patient Navigator Network. Once identified, the principal investigator will check to be sure individuals meet the study eligibility criteria and willingness to participate in the research study. For those individuals willing to participate, detailed information regarding the study design and procedures (e.g., purpose of study, risk/benefits, nature of questions asked, time commitment) were provided and all questions were answered. Participants will likely not receive direct benefit from participating in the study.

2.0 SUMMARY OF STUDY

The dissertation study concluded with a final sample of 33 participants including patients with breast cancer, breast cancer patient navigators and patient navigator administrators recruited from Western Pennsylvania and took place between November 2017 and April 2018. The purpose of this dissertation study was to 1) identify key interpersonal communication components of patient navigation, 2) prioritize the identified interpersonal communication components and explore their relative importance and 3) understand the relationships among these identified interpersonal communication components and the patient-navigator relationship.

The dissertation project consists of four complementary studies to address several gaps in the scientific literature related to interpersonal communication in breast cancer care patient navigation. The findings are discussed in the following four manuscripts: Manuscript #1: a critical analysis describing the influence of power and privilege in interpersonal communication in healthcare; Manuscript #2: stakeholder engagement for study planning and to preliminarily explore the interpersonal communication components of patient navigation; and Manuscripts #3 and #4: which share the results of a concept mapping study to explore the key interpersonal communication components of patient navigation and illustrate the relationships between these components and the patient-navigator relationship.

2.1 PROPOSAL MODIFICATIONS

Throughout the course of this project, several modifications were made to the proposed study methods. These changes, along with the rationale for these changes, are provided below.

Concept Mapping Focus Prompt: The focus prompt was revised with stakeholder input through working with a local breast cancer advisory group. The final focus prompt was shared by email with the larger advisory group and was also approved by the dissertation committee members.

Recruitment: Due to the inability to recruit directly from additional cancer centers outside of Magee Womens Hospital, the Pitt+Me Research Registry through the University of Pittsburgh Clinical and Translational Science Institute was utilized. The registry includes more than 107,000 participants and individuals from several UPMC facilities and Western Pennsylvania. They are consented to be contacted for potential participation in research studies. If patient navigators recruited participants for this study, there was a concern of selection bias. To reduce potential bias in recruitment, flyers were placed in the oncology clinic at Magee Womens Cancer Center. Also, study information, including the Pitt+Me link, was shared through a local breast cancer support group's social media page. Snowball recruitment was added to assist in reducing bias, allowing one participant to identify another who may be interested. Instead of sharply delineating the recruitment step from the second step of sorting and rating, recruitment was extended into the second step of the dissertation study.

Participant Eligibility: To expand the number of patients that would be eligible for the study but still reduce the influence of recall bias, patients with breast cancer who had communicated with their navigator within the last six months were included, instead of three months as indicated in the original proposal.

Incentives for participants: Originally, participants were going to be given a one-time payment for participation. However, the payment was distributed across the different steps of the concept mapping study, with participants receiving \$10 for brainstorming, \$10 for sorting/rating, and \$30 for the interpretation session, to promote retention in the study and account for those participants that were not able to complete all study steps.

Concept Mapping Master List: The original proposal mentioned limiting the master list to seventy-five statements. However, after synthesizing the brainstorming statement list, eighty-five statements remained. There was a risk of losing some of the original statement meanings through continued synthesis.

Interpretation Sessions: We originally intended to conduct all the interpretation sessions in-person; however, web conferencing was more suitable for the administrators. This group was small and geographically dispersed. In the original proposal, we also planned to take two concept map solutions to the interpretation session allowing participants to choose. However, it was agreed that one final solution would be offered in the group sessions to allow more discussion of the statements within clusters, cluster naming and diagramming the relationship between clusters.

2.2 CONCLUSIONS, IMPLICATIONS FOR NURSING AND FUTURE STUDIES

Overall, this dissertation study has both strengths and limitations. This study seeks to expand and challenge our current understanding of interpersonal communication, particularly in patient navigation. No study has specifically examined interpersonal communication skills, practices and behaviors in breast cancer care navigation. Engaging stakeholders, specifically patients, in the

planning, data generation, analysis, and interpretation, is key to enriching the understanding of the interpersonal components of patient navigation. Furthermore, the application of quantitative analyses to qualitative data through the concept mapping process produces visual representations of the participant perceptions to guide future models of patient navigation and potentially patient navigator training. The first two study steps were intentionally online to promote participant retention based on input from key stakeholders. This design may have limitations including, the absence of group dynamics during the brainstorming and sorting and rating steps. These online steps also lengthened the time needed to participate in the study. Utilizing one patient navigator to identify potential patient participants may have introduced bias into the sampling and recruitment procedures. Furthermore, accurately combining the large number of brainstormed statements into a manageable but representative master list was also challenging. There was duplication of ideas through the online brainstorming. Perhaps this would have been avoided through in-person meetings.

In conclusion, this dissertation provides an increased understanding of the range of factors that impact interpersonal communication in breast cancer care navigation, has engaged with key stakeholders at multiple levels throughout the research process, and facilitated collective work towards next steps. Taken together, these findings have implications for both nursing science and global health as patient navigation continues to expand outside of oncology to other conditions, populations, and countries. Nurses represent a large proportion of those in the role of a patient navigator. Knowledge gathered from this work suggests future work is needed in this area and includes:

1. Development and testing of guidelines, best practices and training for patient navigators.

2. Continuing to expand the evidence base for patient navigation and its impact on patient outcomes.
3. Descriptive studies are needed to identify outcomes measures utilized by patient navigation programs and how these evaluations were implemented across systems.
4. Informing health policy around patient navigation services.

3.0 MANUSCRIPT #1: POWER AND PRIVILEGE: A CRITICAL ANALYSIS OF INTERPERSONAL COMMUNICATION IN HEALTHCARE

3.1 ABSTRACT

Background and Purpose: Interpersonal communication is critical for improving patient-provider encounters and is a core competency for patient navigators. While widely used, this concept is vague, understudied and requires enhanced clarification in order to promote equity in health communication. The purpose of this study was to provide a critical analysis of the concept of interpersonal communication in healthcare.

Methods: Through a review of the scientific and theoretical literature, we systematically investigated the concept of interpersonal communication and through a critical lens examined definitions, antecedents, defining attributes and consequences of the concept.

Findings: Interpersonal communication in health has been widely characterized in the health communication literature. Key components of this concept include: both verbal and nonverbal communication patterns, patient-centeredness, ethics, the role of technology as well as the larger social context of patients and providers.

Conclusion: While interpersonal communication in health is a concept frequently discussed and prioritized in health communication, there is a gap in the current literature addressing the intersections of race, gender and social class in interpersonal communication. Thus, patient

navigation has both the opportunity and the challenge of prioritizing the voices of underrepresented groups as it develops and conceptualizes interpersonal communication.

Clinical Relevance: As health inequities continue to impact the health of our communities, it is key for health care providers to reflect and evaluate discrimination in the medical encounter.

Keywords: interpersonal communication, health communication, health equity

3.2 BACKGROUND

Interpersonal communication in healthcare is a commonly identified competency for many health professions and plays an essential role in the medical encounter (Cohen, Scott, White & Dignan, 2013; Englander et al., 2013; Epstein & Street, 2007; Lubejko et al., 2016). Similarly, in the growing field of patient navigation in cancer care, interpersonal communication is essential to improving the patient navigators' ability to build trust, provide culturally appropriate and relevant care, develop rapport, provide psychosocial support, increase the patients' participation in care and address patients' barriers to care (Jean-Pierre et al., 2011; Nguyen, Tran, Kagawa-Singer & Foo, 2011; Philips et al., 2014; Yosha et al., 2011). Not only is interpersonal communication a key task for oncology patient navigators, it is also a noted area for professional development (Lubejko et al., 2016; Pratt-Chapman, Willis & Masselink, 2014).

While interpersonal skills have been identified as a core competency for patient navigators, the particular interpersonal components of breast cancer patient navigation that influence the ability of patients to overcome barriers to care is understudied (Cohen et al., 2013). A broader, more inclusive understanding of interpersonal communication in patient navigation will be important as competencies and trainings for patient navigators continue to be refined. Especially

as patient navigation was designed to mitigate health disparities in breast cancer care, it is important to question and challenge our current understanding of interpersonal communication, examining how it may be marginalizing to underrepresented groups and ensuring that this concept reflects the needs of these populations. Thus, the purpose of this article is to provide a critical analysis of the concept of interpersonal communication in healthcare.

3.3 METHODS

In this paper, a concept analysis was conducted to examine the concept of interpersonal communication in healthcare. The concept analysis is an important step in refining ambiguous concepts in a theory, clarifying overused or vague concepts and developing a conceptual definition of a concept. In this analysis, we systematically and logically investigated the concept of interpersonal communication by developing a clear definition, identifying antecedents, defining attributes and consequences of the concept, and developing a model case (Jaccard & Jacoby, 2010; Walker & Avant, 1995).

In addition to the traditional components of the concept analysis, this analysis also seeks to incorporate a critical lens at each step through the application of an oppression framework in the review of the literature. An oppression framework promotes expanding to other theoretical schools of thought, such as feminist theory and critical race theory, which provide new ways from which to examine the intersection of race, ethnic background, gender and social class (Baker Miller, 1986; Bohman (n.d.); Gilligan, 1982). Through the incorporation of the voices of

commonly underrepresented groups, such as women and people of color, the goal is to produce a more meaningful and relevant conceptualization of interpersonal communication.

The review of the scientific and theoretical literature included relevant articles and information retrieved from both PubMed, Google Scholar, as well as searching reference lists, conference abstracts and other grey literature. The key concepts, keywords and MeSH terms included: “Patient-provider communication”, “interpersonal communication”, “effective communication”, and “interpersonal skills”.

3.4 RESULTS

3.4.1 Definitions of the Concept

While interpersonal communication is a common concept across a variety of disciplines, there is little agreement as to just how the concept should be defined. At its most basic level, the word interpersonal is defined by Merriam-Webster Dictionary as “being, relating to, or involving relations between persons.” (Merriam-Webster Dictionary, n.d.). Communication is defined as “a process by which information is exchanged between individuals through a common system of symbols, signs, or behavior.” (Merriam-Webster Dictionary, n.d.). In the area of social psychology, communication at the interpersonal level involves a process that allows participants to simultaneously affect one another (Krauss & Fussell, 1996). Looking at these concepts through a philosophical lens, the philosopher, Martin Buber, emphasized the notion of human existence as an encounter with others and the world; and dialogue, or language-oriented communication, is one way of expressing the interpersonal nature of human existence (Zank & Braiterman, 2014). An

ethics perspective emphasizes the need to sustain and nurture dialogic interaction as a key component of communication, where both participants are considered worthy of respect and allowed to express their own points of view. More specifically in the health sciences and health communication literature, interpersonal communication is commonly seen as the ability of the provider to elicit and understand patient concerns, explain health information and foster shared decision-making (Beaulieu et al., 2011; Roter & Larson, 2001).

Alternative to the view of the traditional patient-provider dyad where the patient is the receiver of the message from a more powerful, knowledgeable informer, patients are active participants who interpret, manage and create the meaning of their health and illness (Vanderford, Jenks & Sharf, 1997). From a critical health communication praxis perspective, the focus of interpersonal communication centers around a self-serving discourse and a paternalistic exercise, where those messages of health care providers are privileged over the health beliefs of those not in authority (Lupton, 1994). Furthermore, through a feminist lens, interpersonal communication involves relationships that are influenced by gender, informed by patriarchal histories, and subject to cultural and institutional inequalities (Manning & Denker, 2015).

3.4.2 Defining Attributes

Key attributes of interpersonal communication include: verbal and nonverbal communication, communication style, and patient-centeredness. Commonly health care providers are taught certain norms for communication, including verbal and nonverbal communication and communication styles that will promote patient-centered care. However, often these norms do not consider the diversity in communication preferences influenced by power differentiation, gender, race, and class. This need for diversity presents a challenge for providers and a needed area for clarification

as we begin to identify essential interpersonal skills for patient navigators who primarily serve marginalized individuals.

3.4.2.1 Verbal and Nonverbal Communication. Verbal communication is a key player in the medical encounter between a provider and patient. There are some categories of verbal communication that are commonly utilized during the medical interview including data gathering, education and counseling (Roter et al., 1997; Roter & Hall, 2004; Roter & Larson, 2001). However, the medical encounter can also be an opportunity for patients to relay their narrative and experience. A less commonly emphasized category of verbal communication is partnership building, where providers promote patients being active participants in the encounter by seeking patient input, checking for provider understanding and taking on a less-dominating stance, such as being less verbally dominant (Roter et al., 1997; Roter & Hall, 2004; Roter & Larson, 2001). Less emphasized, but equally powerful, is the role of emotionally responsive communication which includes verbal behaviors that foster positive talk including agreements, approvals, compliments and social talk to convey friendliness and personal regard.

Furthermore, medical language is not value-free and can be interpreted as emphasizing the perceived inferiority of another. The verbal communication utilized during the medical visit does not exist in isolation but is part of a broader social discourse and is reflective of microstructures and macrostructures in which they are embedded (Lupton, 1994). For example, medical jargon contributes to perpetuating stereotypes of women through its emphasis on physical inferiority, hormones, and the function of their bodies for reproduction (Lupton, 1994). It is critical to be aware of what meaning, values and inequalities providers adopt during the medical encounter

through the use of descriptive language, traditional medical language, and even nonverbal behaviors that feel comfortable to them as providers but may not be culturally sensitive.

Non-verbal communication typically revolves around facial expressions, gestures, posture and physical barriers such as distance from the patient. Common expressions include eye contact and touch, which have been associated with the development of understanding, trust, empathy, and rapport (Montague, Chen, Xu, Chewning & Barrett, 2013). However, nonverbal cues can also lead to feelings of not being accepted, a sense of insecurity for patients and may impede further communication. Moreover, nonverbal communication may be seen as subtle communications of social power. In a study by Carney, Hall and Lebeau (2005), psychology students identified several nonverbal behaviors that differ between individuals based on their perceived level of social power. Some of these nonverbal behaviors for higher powered individuals included paying less attention to the less powerful person in the interaction, initiating more hand shaking, engaging in more invasive behavior, having less gaze aversion, expressing less fear or sadness, more likely to gesture, orienting the head toward the other, leaning forward more and having an open body position (Carney et al., 2005). Additionally, persons with higher social power were expected to be more likely to have self-assured expressions, express intimacy in greeting, use fewer “um”s and “ah”s, have more successful interruptions, and fewer pauses in speech (Carney et al., 2005).

3.4.2.2 Communication styles. There are several types of health communication styles that have been identified that both promote and inhibit good interpersonal communication during the medical visit. Communication styles that were the most highly associated with increased patient and provider satisfaction are those that promote more of a balance between psychosocial and biomedical information, less data gathering and information giving and more emotionally positive

speech and social talk (Roter et al., 1997; Roter & Hall, 2004; Roter & Larson, 2001; Roter, 2010). The utilization of different communication styles is influenced by provider type, years of experience, gender concordance of provider and patient, racial concordance of provider and patient as well as the level of complexity of the visit (Roter et al., 1997; Roter & Hall, 2004; Roter & Larson, 2001; Roter, 2010).

It is interesting to note that even these commonly accepted communication styles have limitations, specifically addressing underrepresented populations, such as the acknowledgement and incorporation of feminine communication styles. This is compounded by the lack of current literature that incorporates discussions of gendered communication patterns in healthcare. Traditionally, feminine communication styles suggest that many women use talk as a primary way to create and maintain relationships (Ellingson & Buzzanell, 1999). Thus, if a provider is sending signals, both verbal and nonverbal, that they are not interested in talking with a patient, such as avoiding eye contact or remaining standing, this may impede the interpersonal communication between the patient and provider and ultimately the patients trust in the provider. A feminine communication style also emphasizes the need for hopeful and encouraging messages and showing empathy both verbally and nonverbally (e.g. facial expressions and touch). Equality is also important in these communication styles as it lends itself to a more participatory method of interaction through being encouraged to ask questions, share personal experiences and bringing up new topics (Ellingson & Buzzanell, 1999).

3.4.2.3 Patient-Centeredness. Patient-centeredness is also a defining attribute in interpersonal communication and has been well supported in the broader literature. It is defined as “health care that establishes a partnership among practitioners, patients and their families to ensure that

decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care" (Agency for Health Care Research and Quality [AHRQ], 2015, p. 181). Patient-centeredness also incorporates elements of tailoring information in response to a patient's concerns, beliefs and expectations (Epstein, Fiscella, Lesser & Stange, 2010). By emphasizing a healing relationship, patient-centered communication has many positive outcomes, including improved health status and reduced medical costs (AHRQ, 2015; Epstein et al., 2010).

Nevertheless, Ells, Hunt and Chambers-Evans (2011), offer a critique of patient-centered care, particularly in its conceptualization of patient autonomy and the assumptions that exist in clinical culture that may isolate patients in decision-making. Thus, the authors suggest a new feminist formulation of autonomy called relational autonomy. According to the authors, relational autonomy identifies the social nature of people's lives which is intimately connected to economics, politics, ethnicity, gender, and culture (Ells et al., 2011). Therefore, in this approach, autonomy becomes dynamic influenced by the structure of people's relationships and the social context in which they find themselves that can both facilitate or impede their ability to exercise autonomy (Ells et al., 2011). Thus, the challenge to providers is to advocate for fair and supportive social contexts that allow patients to exercise their autonomy (Ells et al., 2011).

3.4.3 Subdimensions of the Concept

Ethics is a core sub-dimension of interpersonal communication it is the mechanism by which providers apply consistent values to clinical care as well as promote and protect the well-being of patients. One of the basic tenets of biomedical ethics is justice, which addresses the equal distribution of care. Current ethical concerns related to interpersonal communication include the

influence of power dynamics and social status and their impact on health equity. Many health communication encounters and contexts involve those with more power, the provider, trying to influence or help those with less power, the patient. Historically, medicine is considered patriarchal, bringing with it associated power and status differences which produce structured relations of inequality (Govender & Penn-Kekana, 2007; Strasser & Gallagher, 1994). To address these concerns of justice and health equity, a communication action ethic, guided by critical and feminist theory, promotes a power transformation in the medical encounter (Smith, 1996). Patients and providers are able to examine existing norms and mutually create new ones to guide the relationship moving forward (Smith, 1996). Mutual understanding establishes an interaction where each person respects the other's reasoning, emotions and encourages authentic participation without persuasion, pressure or manipulation to achieve an end goal (Smith, 1996).

Technology is also increasingly becoming an essential sub-dimension of interpersonal communication conversations as it becomes more prevalent in health encounters between providers and patients, both in-person and online. Consumer health informatics envisions the potential of communication technologies to improve physician-patient communications. However, research is needed to determine how technology-mediated encounters impact the development and maintenance of good interpersonal communication between providers and patients, including how electronic health records (EHR) can promote patient engagement in their care and how the digital divide and inequalities in access to communication technology may further impede care (Ackerson & Viswanath, 2009; Deuthsch et al., 2013).

3.4.4 Antecedents

Interpersonal communication does not occur within a vacuum but is highly influenced by the context surrounding the interaction. Needs of the provider and the patients underlie the motivation in any health communication. Values, beliefs, principles and qualities as well as communication skills necessary to convey both verbal and non-verbal messages and understand and interpret those messages are also fundamental to the interpersonal context of communication. (Hall et al., 2015). Furthermore, the emotions of the provider and patient, both positive and negative, can influence the individual's subjective experience, body language and social expressions (Hall et al., 2015).

Commonly, the provider-patient encounter is described by marginalized patients as discriminatory and mirroring the social stratifications of society at large (AHRQ, 2015). These experiences of discrimination and poor communication are frequently noted by less wealthy individuals, women and can be further mediated by race or ethnicity, religion and language group. Thus, suggesting that social distance between the provider and patient is important in shaping the interpersonal communication in the health encounter (AHRQ, 2015; Govender & Penn-Kekana, 2007; Hall et al., 2015). This social context of interpersonal communication is a combination of both the patients and provider's characteristics and experiences as well as the social, cultural, legal and physical aspects of the environment (Ackerson & Viswanath, 2009).

For example, racial discordance between the provider and patient may produce lower levels of trust, participation in care, and positive affect (Cooper et al., 2012; van Ryn, 2002). Patient markers of social class, including education and income, can also affect communication. There are several common characteristics related to poor communication received by people of color, persons with lower education or living in poverty. These include using dominant communication patterns where providers did not explain information in a way they could understand, showing less

respect for the things told to them, expressing fewer positive emotions, allowing less input on treatment decisions, and being less patient-centered (AHRQ, 2015; Hall et al., 2015; Johnson, Roter, Powe, & Cooper, 2004).

While both patient and provider behaviors may be explanatory factors in health inequities, it is important to include discussion of the role of provider bias (van Ryn, 2002). These implicit biases may influence their interpretation of symptoms, clinical decision making, interpersonal behavior, and treatments prescribed for racial and ethnic minorities (van Ryn, 2002). Moreover, higher implicit bias among physicians impacts specific aspects of communication, including having slower and less patient-centered speech, more verbal dominance, less clinician and patient positive affect and fewer rapport building nonverbal cues (Cooper et al., 2012; Elliot, Alexander, Mescher, Mohan & Barnato, 2016; Johnson et al., 2004). These biases are not only limited to race and ethnicity but extend to other social categories as well including gender, age, socioeconomic status and illness (Penner et al., 2016; van Ryn, 2002).

3.4.5 Consequences

Improved patient outcomes are a common metric in assessing the quality of interpersonal communication between providers and patients. Common outcomes measurements are patient satisfaction, the quality of health care, adherence to medical treatment and recall of medical information (Ackerson & Viswanath, 2009; Ellingson & Buzzanell, 1999; Ells et al., 2011; Epstein & Street, 2007; Govender & Penn-Kekana, 2007; Krauss & Fussell, 1996; Roter et al., 1997; Roter & Hall, 2004; Roter & Larson, 2001; Roter, 2010). However, the conceptualizations of common metrics such as patient satisfaction, may not accurately capture the experience of certain groups or allow for differences in gender, social class or race. Due to the lack of current literature critically

evaluating patient satisfaction, it is important for future research to critically analyze our current measurements of patient satisfaction and ensure that it captures the many ways underserved groups conceptualize patient satisfaction in the context of interpersonal communication. Thus, this paper identifies the need for a new measurement paradigm that incorporates power dynamics and the context of patient's lives into measuring outcomes of interpersonal communication.

3.4.6 Implications for Practice

Providers may find themselves wondering how the conceptualization and critical analysis of interpersonal communication in health translates into practice. Thus, the following exemplar is provided to model two cases that provide a comparison of interpersonal communication in the context of patient navigation.

The scenario revolves around Ms. Smith, an African American patient who is suffering from neuropathy as a side effect of her breast cancer treatment. Her patient navigator, Sharon, a white female nurse, comes to speak with her about her neuropathy pain medication. In the first scenario, Sharon, enters the room and greets Ms. Smith, who is seated, with a simple greeting and shakes her hand. As Sharon remains standing with her clipboard to her chest, she quickly mentions that Ms. Smith's provider mentioned she was not taking her neuropathy medication because she could not afford it. Ms. Smith nods with a confused look on her face. As Sharon continues to ask a few questions, she remains standing and glances down at her watch frequently. Then, she hands Ms. Smith some information with numbers of organizations that provide financial assistance to help pay for medications and suggests calling one of those. Is there anything else I can help you with today, Sharon asks? The patient says no and then leaves.

In the second scenario, Sharon enters the room, greets Ms. Smith with a smile. Sharon sits down next to Ms. Smith and explains that her provider mentioned she was struggling paying for the medications that helped with the pain in her legs. I'm sorry, a lot of people have a hard time paying for medication, Sharon says. What do you think would be the best way I could help you? Mrs. Smith mentions it is the copay, it is just too high. Sharon says that she'll talk with the pharmacist and the nurse practitioner to see what options there are for getting a generic version of the medication or see if there is some financial assistance. Sharon then continues with a quick psychosocial check in, due to Ms. Smith's closed posture and sad facial expression. Sharon asks about pain and the patient goes on to explain how it is affecting her sleep and really her mental health. As they wrap up their conversation, Sharon makes sure to ask her how her daughter is doing with her new baby? As they are leaving the room, Sharon asks if it okay to offer her a hug, and hugs Ms. Smith after she consents. Before she leaves, Sharon mentions that she'll follow-up with Ms. Smith tomorrow to let her know what she figured out.

In evaluating these scenarios, it is important to point out Sharon's use of social talk in the second scenario which allowed her to be emotionally responsive but also support the gendered nature of communication. The second scenario also showed more shared decision making to promote equality in the relationship. In the first scenario, the patient navigator makes assumption about the trouble Ms. Smith is having with paying for medications and also makes assumptions about her closed posture, not thinking that it could be due to pain or other areas of the context of the patient's life. Overall, there are many ways in which the interpersonal interactions between patients and providers may unfold. Therefore, taking the time to critically analyze how the interpersonal context is more than words and kind gestures and is a place where power dynamics

can subtly place a barrier to communication between patients and providers is important to continually challenging ourselves to provide the best care possible to patients.

3.5 CONCLUSION

As part of this critical analysis, it is also important to account for my positionality as the researcher. My interest in utilizing a critical analysis began with my introductions to the tenets and principles of feminist theory, critical race theory, and emancipatory inquiry. When first introduced to these discourses, my research interests were already centered around health equity. My participation in these critical theory discourses enabled me to find guiding frameworks helping me to better understand both microstructures and macrostructures that we find ourselves a part of and provided me a new lens from which to view my equity focus.

This critical analysis of the concept of interpersonal communication in health has provided a broad overview of some of the conceptualizations of interpersonal communication from both traditional and current research. This analysis has identified, through the application of a critical lens, that many conversations surrounding interpersonal communication still do not adequately address the underrepresentation of groups that experience discrimination or inequality within our healthcare systems. The lack of up to date literature addressing the limitations of our current understandings of interpersonal communication calls for a revival of the application of these critical theories to guide the expansion and strengthening of our conceptualization of interpersonal communication in health.

This analysis also provides a critical perspective at a crucial time in patient navigation's ongoing development, understanding and conceptualizations of interpersonal skills and

communication as key competencies for patient navigators. Patient navigation, as a relatively young field which continues to grow and expand across the United States, has a wonderful opportunity to intentionally bring to the forefront the voices of underserved groups and apply a critical analysis to ambiguous definitions and widely-accepted key components of interpersonal communication in the health care context.

4.0 MANUSCRIPT #2: EXPLORING STAKEHOLDER EXPERIENCES WITH INTERPERSONAL COMMUNICATION IN PATIENT NAVIGATION: A BRIEF REPORT

4.1 ABSTRACT

Background: Interpersonal communication in breast cancer care navigation is considered to be important but is poorly defined. This limits training and evaluation of patient care services. Concept mapping, a community-engaged research method, calls for the active participation of participants throughout the research continuum including preparation, data collection, sorting of results and contextualization of findings. This paper reports on the first step of a concept mapping study, where key stakeholders identified components of interpersonal communication in breast cancer care navigation. These key informants were also essential in the overall planning of the larger concept mapping study.

Method: A qualitative design was employed. Six thirty-minute, semi-structured interviews were conducted with six participants: three women with breast cancer who had experienced patient navigation, two breast cancer patient navigators and one patient navigator administrator. Qualitative content analysis was utilized to analyze the interviews.

Results: Four themes were identified related to the participants' experiences with interpersonal communication in breast cancer patient navigation: support, personalization, responsiveness and patient navigator characteristics.

Conclusion: This stakeholder engagement study allowed the preliminary exploration of the key components of interpersonal communication during patient navigation in order to provide a relevant, stakeholder derived direction for the planned larger study.

4.2 BACKGROUND

Patient navigation, the assistance by an individual, either lay or medically trained, who helps patients to identify and address barriers to care to prevent attrition from and promote the patient's progression along the cancer care continuum, is a well-established intervention. Communication and interpersonal skills are identified as key competencies for patient navigators, yet the exact components of interpersonal communication in patient navigation are not well studied, particularly in cancer care patient navigation (Cohen et al., 2013; Lubejko et al., 2016; Pratt-Chapman, Willis & Masselink, 2014).

Community-engaged research is an important approach for addressing health disparities and increasing the use of scientific evidence in communities (Hacker, 2013). A specific strength of a community-engaged approach is that participants are active throughout the research process, especially during study planning. The involvement of community partners allows for shared ownership between the community and researchers, which can improve the community's acceptance of research, facilitate a deeper and more informed understanding of the research question, and inform the research process (Hacker, 2013; Israel et al, 1998).

In concept mapping, a community-engaged research method, participants help to plan the research, assist with the process of data collection, prioritize the results and ensure that the results accurately represent the perspectives of participants versus that of the researcher (Burke et al.,

2005). This stakeholder engagement study sought to involve key stakeholders in the planning process in order to facilitate a more precise execution of a larger descriptive study utilizing concept mapping to explore interpersonal components of patient navigation in breast cancer care.

4.3 METHODS

This was a qualitative inquiry utilizing semi-structured interviews with identified stakeholders (patients, patient navigators and patient navigator administrators). The semi-structured interviews focused on the relevance of the proposed research question of the larger concept mapping study. The interview explored key stakeholders' experiences with the interpersonal components of patient navigation, assessed the concept mapping focus prompt for clarity and usability, and gathered input on appropriate recruitment and retention strategies for the larger study. This report describes the qualitative findings related to stakeholder experience with interpersonal communication in patient navigation.

The inclusion criteria included being a patient with breast cancer working with a patient navigator, a patient navigator in breast cancer care, or an administrator supervising patient navigators in breast cancer care. Patients with a history of patient navigation from a cancer center in Western Pennsylvania were asked to participate. Participants were identified by a patient navigator and, if willing, were referred to the principal investigator. Patient navigators and administrators involved in patient navigation were identified and contacted by phone or email by the principal investigator.

The study protocol was reviewed and approved by the University of Pittsburgh Human Research Protection Office (See Appendix C). Once identified, potential participants were

contacted by phone to setup a time to conduct the interview and provided an overview of the stakeholder engagement study. Individual interviews were conducted in-person, audiotaped, and transcribed. Each interview lasted about thirty minutes.

Inductive content analysis was used to analyze the transcripts through open coding by writing notes and heading on the transcripts, creating categories and deriving themes from the categories (Elo & Kynegäs, 2008). To improve the credibility of the results, two researchers independently read through the transcripts and identified categories (Creswell, 2013). They then met to review each other's categories and discuss any discrepancies until consensus was met and final thematic categories were identified.

4.4 RESULTS

A sample of 3 patients, 2 patient navigators and one patient navigator administrator were recruited. Participants represented two different health systems in Western Pennsylvania. Analysis of six thirty-minute interviews yielded four overarching themes of interpersonal communication in patient navigation: (1) support, (2) personalization, (3) responsiveness, and (4) patient navigator characteristics. These themes are described in the following sections.

4.4.1 Support

Support is defined as navigators providing care and communication to patients by being available, referring to resources and keeping them aware and knowledgeable. Participants noted the need for

patient navigators to be available and easy to contact, with one patient saying, “You know if I emailed her, she would call me right back. You know, if I called her, she would call me right back.” Participants also thought that patient navigators should provide support through education and referrals to resources specific to the patient’s situation, including underutilized or hidden resources: “Her telling me other resources that are out there was definitely helpful. I mean, I wouldn’t have known that existed.” One key piece to the support offered through patient navigation is the initial relationship building and trust as well as the ongoing relationship, which can extend to meetings outside the hospital, to other parts of their cancer care or even checking in after treatment is completed. One patient noted, “It’s definitely nice to have one person to see you through to the end.”

4.4.2 Personalization

Personalization encompasses the individual assistance navigators provided patients in obtaining care for themselves. One patient said, “She [navigator] was very helpful in helping me navigate ways to, um, find help and resources that were specific to my situation.” Patients and patient navigators pointed out that this tailored support also includes utilizing different forms of communication depending on the individual’s preferences: “I do think that the face-to-face communication is the best” (patient). “So I try and like, when I’m communicating with them, kind of like do different methods, I know not everyone is like a verbal learner” (patient navigator). One patient navigator pointed out that the ongoing relationship between the patient and navigator also includes a level of familiarity, “I get to know their families, I make a notation on my assessment

sheet if someone is working 2 jobs, if someone is a single parent, if someone's children are out of town. I want to put a face with that person because you need to do that.”

Tailoring also occurs through navigators recognizing that patients cope and manage anxiety and emotions that come with a cancer diagnosis differently. Participants commented on the need to normalize feeling and to avoid shaming, “there’s a fine line between being not hard on the patient but empowering that patient to do the things they need to do to get care.” (administrator).

4.4.3 Responsiveness

Navigators are responsive when they are open and flexible to address patient preferences and show consistent follow-up to patient needs and questions through prompt and positive responses. Participants voiced the importance of the patient navigator being a point person: “Just being able to contact her like as my point person any time, you know, I had a question or needed any help or support or someone to cry to.” The responsiveness of the navigator positively impacts the patient’s feeling of support and lessens distress, “I remember being at the bird aviary with my son and just crying there and she would call me back. I mean like it’s just, you just want to know that there’s somebody there that you can get.” Responsiveness also means that patients receive a prompt response by patient navigators and that stress of uncertainty can be mitigated by understanding and anticipating what the patient may need during different aspects of their cancer care: “I think that’s a good point a lot of times that I don’t have to go to them [navigators], searching out the answers, because they’ve already been presented to me ahead of time.”

4.4.4 Navigator Characteristics

There are specific characteristics that promote improved communication in the navigator role including active listening and being empathetic, passionate, relatable, knowledgeable and affable. Empathy was commonly emphasized among participants, with one patient noting, “I just think it’s about how they are when they are speaking to you. Did they seem engaged? Did they seem like they care? Did they, you know, show empathy? Or did it just seem like they were checking off the box?” Being knowledgeable, including understanding and connecting patients with quality and reliable information about cancer, cancer treatment, resources such as financial assistance, and clinical trials was also emphasized. Active listening was also identified as key across all participant groups, with one navigator noting, “You need to connect with the patient and read their body language and listen to them.” One navigator also mentioned the importance of being passionate and connecting to patients through commonalities which makes the experience more relatable and open and honest. Navigators should also be friendly, with one patient noting “I would say that she was just very, um, easy to talk to, you know.”

4.5 DISCUSSION

This study has added to the literature concerning interpersonal communication components of breast cancer patient navigation from the perspective of key stakeholders. Findings underscore the importance of specific skills and behaviors of patient navigators that support individuals as they navigate breast cancer care.

In the broader patient navigation scientific literature, emotional and interpersonal support is increasingly acknowledged as a key task of patient navigators (Gunn et al., 2017; Philips et al., 2014; Rousseau et al., 2014). This study has highlighted the importance for patient navigators to be responsive through being available and serving as a point person who is easily contacted and streamlines the process. The patient navigator's prompt response, support and ability to anticipate patient needs also play a key role in the interpersonal communication between patients and patient navigators.

A better understanding of the skills, behaviors and practices that promote a positive patient-navigator relationship is key to future research in patient navigation. The patient-navigator relationship has consistently been identified as central to patient navigation services and is an important aspect of patient navigation suggested to result in health benefits to patients (Jean-Pierre et al., 2011; Philips et al., 2014).

5.0 MANUSCRIPT #3: USING CONCEPT MAPPING TO EXPLORE INTERPERSONAL COMMUNICATION COMPONENTS OF PATIENT NAVIGATION IN BREAST CANCER CARE

5.1 ABSTRACT

Background: Patient navigation is an increasingly popular tool used by healthcare systems to address disparities in access to and utilization of cancer care. Interpersonal communication is considered a critically important construct in patient navigation, although there is a lack of established evidence defining its attributes and applications. The purpose of this analysis was to identify the key interpersonal communication components of patient navigation in breast cancer care from multiple stakeholder perspectives.

Methods: This study employed concept mapping, an innovative community-engaged mixed method approach. Concept mapping produces pictorial views of how components of complex ideas are connected and interrelated to facilitate deeper understanding, more precise measurement, and improved application of concepts. In this study, participants completed three concept mapping activities including brainstorming, sorting and rating and interpretation.

Results: Thirty-one participants including patients with breast cancer, breast cancer patient navigators and patient navigation administrators from Western Pennsylvania participated. First, one hundred and twenty-one non-unique items were generated during the online brainstorming activity. These statements were combined into one master list of 85 items. After the sorting and rating step, these 85 items were grouped into a six-cluster concept map. Participants identified

Empathetic, Comprehensive and Compassionate Support, Bridge to Clinical Education and Supportive Resources, and Ongoing Individualized Coordination of Care as the most important components for facilitating the patient-navigator relationship.

Conclusion: These results frame a precise definition of interpersonal communication in breast cancer care patient navigation for training, evaluation and future research.

5.2 BACKGROUND

Despite many advances in cancer treatment and care, inequalities in breast cancer care still exist (American Cancer Society, 2015; Freeman, Muth & Kerner, 1995; Meredith, 2013; Whitman, Ansell, Orsi & Francois, 2011). Racial and ethnic disparities in breast cancer care reflects a combination of individual, healthcare provider and system-level factors. These include access to screening and treatment for cancer, adherence to treatment, stage at diagnosis, education level, and mistrust of the healthcare system (Katz et al., 2014; Meredith, 2013; Tejeda et al., 2013). To address such disparities in cancer care, patient navigator programs were developed with a central aim to help patients address identified barriers to care and navigate the complex healthcare system. Patient navigation is defined, by a broad array of experts, as assistance of patients by non-medically or medically trained individuals in identifying and addressing individual and system-level barriers to prevent attrition and promote patients' progression along the breast cancer care continuum (Freeman et al., 1995; Freeman & Rodriguez, 2011; Jean-Pierre et al., 2011; Vargas, Ryan, Jackson & Freeman, 2008; Whitman et al., 2011).

A review of the literature reveals numerous and diverse documented benefits to patient navigation in the context of breast cancer. Specifically there are increased uptake of mammograms,

reduction in time to biopsy and diagnosis, reductions in time to treatment initiation, and increased patient satisfaction with care (Battaglia et al., 2012; Braun et al., 2015; Dudley et al., 2012; Freund et al., 2014; Hoffman et al., 2012; Hunt, Allgood, Kanoon, & Benjamins, 2015; Lee et al., 2013; Markossian, Darnell, & Calhoun, 2012; Marshall et al., 2015; Mason et al., 2013; Oppong, Dash, Coleman, Torres, & Adams-Campbell, 2016; Percac-Lima, Ashburner, Bond, Oo, & Atlas, 2013; Robinson-White et al., 2010; Shroff et al., 2014; Simon et al., 2015). While these outcomes are encouraging, there is a lack of detail in these studies regarding the patient navigation protocols used, particularly with regard to patient navigator training and role description (Battaglia et al., 2012; Braun et al., 2015; Drake et al., 2015; Dudley et al., 2012; Hoffman et al., 2012; Hunt et al., 2015; Lee et al., 2013; Markossian et al., 2012; Marshall et al., 2015; Mason et al., 2013; Oppong et al., 2016; Percac-Lima et al., 2013; Robinson-White et al., 2010; Shroff et al., 2014; Simon et al., 2015).

Historically patient navigation programs focused on logistically-based interventions, or task-oriented activities such as scheduling appointments, providing education, and other procedural components of patient navigation (Mason et al., 2013; Oppong et al., 2016; Haideri & Moormeier, 2011; Cohen, Scott, White & Dignan, 2013). However, more recently, research in patient navigation has begun to examine the relational dimensions of patient navigation which are much less concrete and more difficult to define (Cohen et al., 2013; Jean-Pierre, 2011; Phillips et al., 2014). Findings pertaining to these relational dimensions indicate that relationship building skills may be more important than task-oriented skills (Bail et al., 2016; Jean-Pierre et al., 2011; Phillips et al., 2014; Yosha et al., 2011). Potentially, it is through the patient-navigator relationship, and its interpersonal components that instrumental functions of patient navigation are enabled and

strengthened, including the ability to identify individual patient barriers (Jean-Pierre et al., 2011; Phillips et al., 2014; Yosha et al., 2011).

The patient-centered communication framework, as well as the social-ecological model for addressing population health, identify the interpersonal framework as the primary context for improving patient-provider encounters and communication (Centers for Disease Control and Prevention [CDC], 2017; Cohen et al., 2013; Epstein & Street, 2007). While impacted by many levels of external factors, the interpersonal context, or encounter between the provider, patient and their family, is a source of factors, such as the provider's perceptions, goals, communication skills and behaviors, that may reinforce or impede the different pathways connecting communication with improved health outcomes (Epstein & Street, 2007). The National Breast and Cervical Cancer Early Detection Program's (NBCCEDP) adapted the Social-Ecological Model to specifically identify patient navigators as potential sources of interpersonal messages and support (CDC, 2017). This further endorsed the importance of interpersonal communication as integral to the patient navigation process.

This focus on interpersonal communication was also acknowledged by The Association of American Medical Colleges (AAMC), Oncology Nursing Society and the George Washington Cancer Institute identified communication and interpersonal skills as core competencies for patient navigators (Englander et al., 2013; Lubejko et al., 2016; Pratt-Chapman, Willis & Masselink, 2014). In a recent nurse navigator role delineation study by the Oncology Nursing Society, participants acknowledged communication as a key task for oncology nurse navigators. Improving communication with patients was noted as a need for professional development (Lubejko et al., 2016).

However, the key components of interpersonal communication in patient navigation that promote positive patient outcomes are understudied (Cohen et al., 2013; Gunn et al., 2017; Jean-Pierre, 2013). Furthermore, the concept of interpersonal communication itself has not been clearly articulated in the patient navigation literature. Defining and identifying the key components of interpersonal communication in patient navigation has implications for the establishment of quality indicators and outcomes on which the efficacy of patient navigation can be measured.

The primary goals of this study were to:

1. Identify key interpersonal communication components of patient navigation in cancer care that patients, patient navigators and patient navigator administrators perceived to impact the patient-navigator relationship.
2. Explore the relative importance of each identified key component in interpersonal communication in patient navigation across groups (patients, patient navigators, administrators).
3. Understand and illustrate the pathways linking key interpersonal communication components to the patient-navigator relationship.

5.3 METHODS

5.3.1 Design

This study utilized concept mapping, a community-engaged research method. As a mixed method approach, concept mapping facilitates the examination and in-depth understanding of the range of factors, both positive and negative, that impact impersonal communication in breast cancer care patient navigation. Concept mapping also facilitates the active participation of participants

throughout the research process including study preparation, data collection, analysis and interpretation (Burke et al., 2005).

5.3.2 Sample and Setting

As per concept mapping methodology, this study utilized purposive sampling to identify potential participants to ensure a broad range of perspectives (Kane & Trochim, 2007). Participants included three stakeholder groups, 1) patients with breast cancer who had interacted with a patient navigator, 2) patient navigators who currently worked in breast cancer care, and 3) administrators who currently supervised patient navigators in breast cancer care. Participant eligibility was based on the following criteria: 21 years of age or older, able to read and write in English, and be available to participate in the three concept mapping steps. Additionally, patients with breast cancer needed to have communicated with their patient navigator within the six months prior to enrollment in the study to reduce the influence of recall bias. This study was reviewed and approved by the University of Pittsburgh Institutional Review Board (see Appendix D for approval letter). Participants could receive up to \$50 via a cash card for their participation, \$10 for completing brainstorming, \$10 for completing sorting and rating, and \$30 for attending the interpretation session.

5.3.2.1 Recruitment. Participants were recruited from Western Pennsylvania between November 2017 and February 2018. Patient recruitment was conducted through several methodologies including: 1) placement of flyers (Appendix E) in the oncology clinic at a cancer center in Western Pennsylvania, 2) advertising through the a research registry, 3) sharing study information on a breast cancer support group's social media page and 4) identification of potential participants by

a patient navigator at a cancer center in Western Pennsylvania. Patient navigator and administrator recruitment included sending study information (Appendix F) by email to the Pennsylvania Patient Navigator Network, sharing study information at local meetings and conferences, and snowball sampling. Those interested were contacted by phone and screened by the principal investigator.

5.3.3 Data Collection.

The data collection and analysis process included the following primary activities: brainstorming, sorting and rating, concept analysis and interpretation. Data collection occurred during three steps in the concept mapping process: brainstorming, sorting and rating. Data were collected utilizing remote input through Concept Systems, Inc., a licensed software program that facilitates the concept mapping process (Concept Systems Incorporated, 2016). The Concept Systems Global Max software allows all data collection to be conducted online (Concept Systems Incorporated, 2016; Walker, Jones & Burke, 2014). For those participants that did not have regular or reliable access to the internet, alternative routes of participation during the online data collection were offered, including mail or in-person data collection options. After a potential participant was contacted, screened for eligibility and provided informed consent, the PI provided them with their unique username and password for the online concept mapping program. Once participants logged on to the online system, they were provided the study information again and then asked to complete a demographic questionnaire (see Appendix G). This questionnaire asked for participants' age, education level, race/ethnicity, income, and years of patient navigation experience (the latter collected only for patient navigators and administrators).

5.3.3.1 Brainstorming. After completing the demographic questionnaire, each participant asynchronously participated in brainstorming, where they were asked to respond to a focus prompt developed in collaboration with a breast cancer research advisory group. The prompt stated, “Please tell me from your experience, what things, both good and bad, a patient navigator says or does during personal communication (e.g., email, phone, face-to-face conversations) that may impact a patient during their cancer care.” The prompt was the same for all participants. The generated statements were synthesized into a master list by two researchers and the PI. Consistent with established concept mapping guidelines, content analysis was utilized to consolidate the list by identifying keywords in the generated statements (Kane & Trochim, 2007). Additionally, duplicate statements were combined to reduce the list to the statements of the final master list (Kane & Trochim, 2007). This master list was uploaded to Concept Systems online for the subsequent sorting and rating step.

5.3.3.2 Sorting and Rating. The Sorting and Rating step was also conducted asynchronously online through Concept Systems Global. The sorting step asked participants to sort the statements on the master list into piles based on their perception of similarity between the statements. Once the factors were sorted into similar piles, participants assigned each pile a label (word or phrase) that described the pile. Participants were instructed to not have too few piles or too many piles. Participants then individually rated each of the statements on a scale of 1 (not important) to 5 (extremely important) for its importance to facilitating a positive patient-navigator relationship (See Appendix H). Participants also rated (1 to 5) the strength of the perceived relationship between each statement and the ability to adhere to the provider’s recommendation as well as the degree to which each statement impacted satisfaction with cancer related care, in concordance with

expert-identified key outcomes to assess in patient navigation (Fiscella et al., 2011; Oncology Nursing Society, 2017).

5.3.4 Data Analysis.

Utilizing the sorting and rating data from individual participants, the core data analyses were conducted through Concept Systems software online. These core data analyses contribute to the development of the concept map (Kane & Trochim, 2007). First, utilizing each individual's sorting data, a similarity matrix, showing the number of participants who sorted pairs of statements together, was created (Burke et al., 2005, Kane & Trochim, 2007). Second, multidimensional scaling was employed to position each statement on a two-dimensional point map through an iterative process (Davison, 1983; Kane & Trochim, 2007; Kruskal & Wish, 1978). After the point map was created, the stress value (the primary diagnostic statistic for multidimensional scaling) was evaluated (Kane & Trochim, 2007). A lower stress value suggests a better representation of the original similarity matrix; the recommended cutoff is 0.365 (Kruskal & Wish, 1978). Lastly, hierarchical cluster analysis divided the statement points on the map into non-overlapping clusters using Ward's algorithm (Burke et al., 2005; Everitt, 1980; Kane & Trochim, 2007). The result was a cluster map, which can range from a single cluster including all statements to each statement in a cluster of its own (Burke et al., 2005; Everitt, 1980; Kane & Trochim, 2007; Trochim et al., 2005). To determine the final number of clusters for the concept map, the range of possible clusters was examined based on the number of piles created by participants during the sorting step. While there is no set standard for selecting the final number of clusters, the PI and another researcher

examined each cluster level within that range, focusing on where clusters merged and deciding if it was better for them to be combined or remain separate.

Subsequent analyses and group comparisons were conducted utilizing participant rating data across all participants as well as between groups of participants (patients, patient navigators, administrators). For this analysis, the focus was on the scale assessing the importance of each statement to facilitating a positive patient-navigator relationship. Individual statement and cluster average ratings for the patient-navigator relationship were calculated for all participants. Using the distribution of statement ratings, the rating levels were categorized into high, moderate, and low (Burke et al., 2009; O'Campo et al., 2005). To facilitate group comparisons and assess consensus, pattern matching displays (ladder graphs) were employed to allow pairwise comparisons by participant type (Kane & Trochim, 2007). Correlation coefficients for the pairwise comparisons were generated (Kane & Trochim, 2007).

5.3.4.1 Interpretation. Data analysis also took place through interpretation sessions. The interpretation sessions were conducted in-person for patients and patient navigators and through web conferencing for administrators. The sessions were facilitated by the PI, and an additional researcher was present to take notes during the discussion. During the session, participants were asked to discuss the final cluster map and create a label that best represented the content of each cluster. They also diagramed how the clusters related to one another and the patient-navigator relationship by using markers and large sheets of paper (details presented elsewhere). The sessions were audiotaped and transcribed to ensure accurate documentation of participant comments.

5.4 RESULTS

5.4.1 Participant Characteristics

A total of 31 persons participated in the study; 13 patients, 14 patient navigators and 4 administrators. Participants represented fifteen different hospitals, cancer centers or organizations from across Western Pennsylvania. The thirteen patients who participated were an average of 54 years old (SD 11.36) and the majority (69.2%) had completed at least some college or technical school (See Table 3). Of the thirteen patients, 53.8% (n=7) of patients identified as white, 38.5% (n=5) identified as black, and 7.7% (n=1) identified as biracial. Additionally, the majority of patients reported lower income with 46.2% (n=6) having an annual household income of less than \$24,999 and 23.1% (n=3) having an annual household income between \$25,000 to \$34,999. Among the fourteen patient navigators and four administrators, most identified as white, 85.7% (n=12) and 100% (n=4) respectively. Patient navigators on average had 3.07 years of experience (SD 2.53) in patient navigation and administrators had on average 13 years of experience (SD 2.45). The patient navigator group consisted of 8 nurse navigators, 2 social worker navigators and 4 lay navigators.

Table 3. Demographics according to participant group.

Variable	Patients (n=13)	Patient Navigators (n=14)	Administrators (n=4)
	Mean \pm SD		
Age	54.31 \pm 11.36	40.57 \pm 13.03	60.75 \pm 2.22
Years Patient Navigation Experience	N/A	3.07 \pm 2.53	13.00 \pm 2.45
	N (%)		
Race/Ethnicity			
White or Caucasian	7 (53.8%)	12 (85.7%)	4 (100%)
Black or African American	5 (38.5%)	1 (7.1%)	0 (0%)
Hispanic, Latino or Spanish origin	0 (0%)	1 (7.1%)	0 (0%)
Asian	0 (0%)	0 (0%)	0 (0%)
Other	1 (7.7%)	0 (0%)	0 (0%)
Education			
Elementary School or Less	0 (0%)	0 (0%)	0 (0%)
Some middle or junior high	0 (0%)	0 (0%)	0 (0%)
Some high school	0 (0%)	0 (0%)	0 (0%)
High school graduate (diploma, GED, or equivalent)	0 (0%)	0 (0%)	0 (0%)
Some college or technical school	9 (69.2%)	0 (0%)	0 (0%)
Associates degree	1 (7.7%)	1 (7.1%)	0 (0%)
4 year college degree	3 (23.1%)	7 (50%)	2 (50%)
Master's, Professional or Doctoral degree	0 (0%)	6 (42.9%)	2 (50%)
Income			
\$24,999 or less	6 (46.2%)	0 (0%)	0 (0%)
\$25,000 to \$34,999	3 (23.1%)	2 (14.3%)	0 (0%)
\$35,000 to \$49,999	0 (0%)	2 (14.3%)	1 (25%)
\$50,000 to \$74,999	2 (15.4%)	2 (14.3%)	0 (0%)
\$75,000 or more	2 (15.4%)	8 (57.1%)	3 (75%)

5.4.2 Interpersonal Communication Components

The brainstorming step generated 121 non-unique items from 24 participants (10 patients, 10 patient navigators, 4 administrators) in response to the focus prompt. These items were synthesized into a master list of 85 statements by two researchers and the PI. Next, during the sorting and rating step, 24 participants (10 patient navigators, 10 patients and 4 administrators) sorted and rated the 85 statements. Participants sorted the statements into a range of 4 to 17 piles with the majority selecting six piles. After conducting the core analysis and reviewing the range of clusters, the researchers determined that a six-cluster map best fit the data (see Figure 3). The stress value for the final six-cluster map was 0.28. On the six-cluster concept map, each of the 85 statements are a point on the map (represented by a statement number). Points that are in close proximity to one

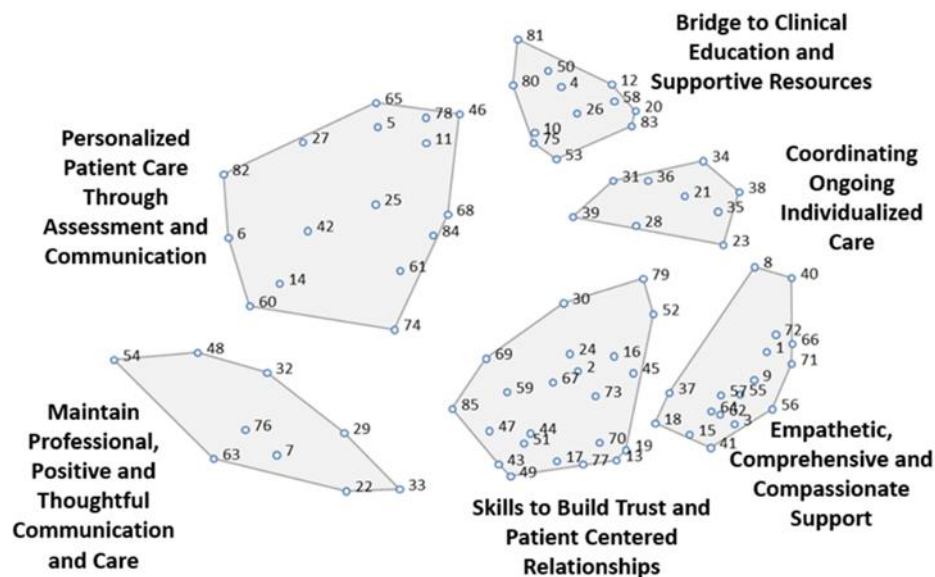


Figure 3. Six Cluster Concept Map

another were considered by participants to be more similar as compared to points that were further apart, which represent statements participants thought were less similar. During the interpretation session, participants developed the names for each of the six clusters, with each session building upon the previous group's cluster names to promote group consensus. The six clusters included: *Bridge to Clinical Education and Supportive Resources*, *Coordinating Ongoing Individualized Care*, *Empathetic, Comprehensive and Compassionate Support*, *Skills to Build Trust and Patient Centered Relationships*, *Maintain Professional, Positive and Thoughtful Communication and Care*, and *Personalized Patient Care Through Assessment and Communication*.

Table 4 presents information about the clusters and the statements within each cluster, which shared a common theme. For example, the *Bridge to Clinical Education and Supportive Resources* cluster contains statements associated with the role of the patient navigator to provide patient education and connect patients to community resources (e.g., statements # 83, 20, 12, 75, 81, 26). Using the distribution of statement and cluster ratings, the ratings were divided into tertiles and designated as low, moderate and high. A low value indicates a rating of 3.12 or lower. A moderate value indicates a rating value between 3.13 and 3.97 and a high value indicates a rating of 3.98 or higher. In examining Table 4, those clusters and statements that received a higher average rating were considered to be more important to facilitating the patient-navigator relationship. For example, the *Empathetic, Comprehensive and Compassionate Support* cluster was rated the most important to the patient-navigator relationship, with an average rating of 4.49. Within this cluster, statements #66, 57 and 72 were felt by all the participants to be most important to facilitating the patient-navigator relationship compared to other statements within the cluster. In contrast, all the participants perceived the cluster, *Maintain Professional, Positive, and Thoughtful Communication and Care* to be less important to the patient navigator relationship,

with an average rating of 3.21. Particularly, items #63, “talking in a rushed or hurried manner”, and #33, telling the patient “I know how you feel”, were considered least important to facilitating the patient-navigator relationship.

Table 4. Eighty-five items within their six clusters and the average ratings for each item's importance to the patient-navigator relationship.

Cluster and item name (item number)	Patient-Navigator Rating
1. Empathetic, Comprehensive and Compassionate Support	High*
From the very beginning they provide support and show they are with you at every step, helping you with anything that you may need during your cancer journey. (66)	High
Actively listens. (57)	High
I am here as support to you and your family. (72)	High
Provide emotional support. (71)	High
Does not discount patients' fears or worries but addresses them with careful explanations of what to expect during an appointment while offering support. (3)	High
Let the patient know that it is okay to feel whatever they feel (sad, angry, whatever it is), it is normal. A positive attitude is not always possible and that is okay. (41)	High
My patient navigator was very empathetic. (64)	High
I am here for you. If there is anything you need please call or email. (37)	High
Direct and inform the patient in a caring and compassionate way through their treatment plan. (40)	High
Listens carefully to what the patient wants to say and needs, even if it's not directly related to screening or diagnosis, whenever possible. A lot of times they feel isolated and don't have many other people to talk to or don't feel they can share with other people. (18)	High
Is there anything we can do for you to make your treatment better? (1)	High
Don't be afraid to offer genuine care and concern for a patient, it is okay to show your human side. (62)	High
She came in and she really cared about the patient, not just doing their job. She would ask me how I'm doing. (56)	High
I always had good information about what I was going through. (8)	High
Provides comfort, such as holding the patient's hand during a biopsy or office appointment, sitting with the patient, or meeting the patient at the hospital if they are apprehensive, assuring them they are not alone. (9)	High
Be encouraging. (55)	High
Always have a personal interest in the patient, their family and kids. (15)	Moderate
2. Bridge to Clinical Education and Supportive Resources	High
Provides verbal as well as written information and resources to the patient (83)	High
Make sure the patient with a new diagnosis has ALL the information they need to make an informed choice about their care (surgical options, genetic testing, neoadjuvant chemotherapy, adjuvant chemotherapy, etc) – no regrets! (20)	High
Provide and connect patients with community or other local resources, such as the American Cancer Society's "Look Good...Feel Better" or the Reach to Recovery program (26)	High
Supply easy to read information on diagnosis and coping. (12)	High
Provide information on various services and supports available in the cancer center and health system (dietician, social worker, integrative oncology). (4)	High

Providing support and information about programs that might help them financially. (80)	High
Provide and connect patient with support groups or other emotional support resources. (10)	High
The patient navigator gives the patient education inform about diagnosis and treatments and helps you understand what's going on with your type of cancer (58)	High
Help the patient with family concerns, how to tell the children, supportive info and hints for the caregivers, even how to ask friends to help with little things. (75)	High
Patient navigator needs to be immersed and informed on the patient's disease specific diagnosis. (53)	High
Directs patients to reputable websites to obtain valuable information. (81)	High
Providing visual resources to the patient (touring the cancer center, showing them what a port looks like, etc). (50)	Moderate
3. Coordinating Ongoing Individualized Care	High
Answers any question the patient has and if they don't know, they get the answers. (35)	High
Provide patient contact information for follow-up, future questions or concerns and encourage to contact as needed. (28)	High
Help them through the process of losing hair (offer donated hand made caps and scarves, where they can get a free wig or purchase if they prefer). (36)	High
Encourage and help the patient to speak with their doctor and ask questions as well as utilize resources. (21)	High
Follow up with patient on a regular basis and certain time points throughout their treatment. (38)	High
Prepare the patient for end of treatment including a warm handoff to the survivorship navigator. Introduce them before the last treatment, making sure the patient knows they can continue to contact you as they return to a new "normal". (23)	High
Check understanding of treatments and treatment options. (34)	High
Call the patient prior to their first visit to acclimate them to simple things and alleviate fears (how to get here or help with transportation, where to park, what to expect when they walk in the door, who will greet them and escort them upstairs, where to go). (39)	High
Explains medical terminology in layman's terms. (31)	High
4. Skills To Build Trust and Patient-Centered Relationships	High
Always courteous and polite. (73)	High
Being sincere. (13)	High
Being a stable contact from beginning of treatment until the end. (79)	High
Establish the rapport with each newly diagnosed patient as early as possible. (16)	High
Have good eye contact with the patient and their family members. (45)	High
Always introduce yourself to them and it's good to ask the name of the spouse or other family members who accompanies the patient. (24)	High
Be aware of non-verbal communication. (59)	High
She was very positive. (43)	High
It is never about the navigator or nurse or staff person, it is only about the patient. (17)	High
Very prompt responses with email and phone. (52)	High

She was available. “As soon as I check in and asked to see her during my treatment, before my treatment was over I would see her.” (69)	High
I am here to make your life as easy as possible during this difficult time. (44)	High
Talk to the patient while sitting at their level. (67)	High
Be comfortable with silence and tears. (19)	High
Always stop whatever busy work is being done when the patient approaches to give them full attention. (2)	High
I don’t always share that I am a survivor, but when it may help the patient to not feel so alone or that the future is hopeless, I will let them know. (70)	High
Tell patients to take one step at a time through this process, especially for those going through chemotherapy. Don’t clog your mind with too many thoughts or questions. Just focus on one thing at a time. (47)	Moderate
When initially told that they have breast cancer, patients become acutely aware of their mortality; therefore, the cancer diagnosis needs to be immediately categorized to decrease those “wild eye emotions”. (85)	Moderate
I am sorry you are going through this. (77)	Moderate
Humor offers a light moment to break the tension, a “mental pause”. (51)	Moderate
Being there for all my appointments. (30)	Moderate
5. Personalized Patient Care Through Assessment and Communication	High
Assess barriers to care (5)	High
Asks if the patient has a good support system at home or with friends (84)	High
Whether or not patient navigation can be offered in a patient’s primary language (14)	High
Ask open-ended questions (74)	High
Act as resource to communicate with various care team members (78)	High
Advocates on behalf of the patient with intimidating financial issues that come up with the healthcare system (financial assistance, incorrect billing, collections, insurance, etc) (46)	High
Be the voice of the patient at breast patient conferences. You may be the only one she confided in that she has a spouse that she is the sole caregiver for, no one else may know, but it could change treatment recommendations (68)	High
After informing the patient of their path results on the phone, facilitate an appointment for them with a breast surgeon (82)	High
Keep acutely connected to the provider’s notes in the electronic medical record, as to anticipate patient reactions (42)	High
Inform you about the easiest and best way to go about it (For example, my navigator would let me know that you have to fill out this by this time and had me the paperwork. She even added sticky notes about where you need to sign) (25)	Moderate
She set up rides for me, I was able to go with Medic Rescue (27)	Moderate
Assist with social work and billing in terms of arranging home care and authorizations for medications/treatments (65)	Moderate
Initially discusses on the phone, the type of cancer and receptor status. If the patient is not receptive to discussing treatment, then details are discussed at their visit with the breast surgeon (6)	Moderate
Develop peer to peer match for patient (11)	Moderate
Provide a purse of hope or satchel of care with a nice note (61)	Moderate
Informing the patient of “bad pathology results” (60)	Low

6. Maintain Professional, Positive and Thoughtful Communication and Care	Moderate
Don't make unrealistic statement/promises suggesting it will definitely be "okay" or "fine" (22)	High
They let you know what is going to work or not or what is available or not right off the bat (32)	Moderate
Do not discuss politics or religion (7)	Moderate
Navigators not given any training or guidelines (54)	Moderate
If children come to treatment or appointments, provide them with coloring or activity books, Play-Doh, etc...or appropriate DVDs with DVD player to borrow (29)	Moderate
Telling a patient you will call them back and then forgetting to do so (76)	Low
When I first talked to a patient navigator, she told me I would get disability in 6 weeks due to compassionate allowance. What she should have said is I would have a determination in 6 weeks. It was almost 7 months until I got my benefits (48)	Low
Talking to the patient in a rushed or hurried manner (63)	Low
I know how you feel (33)	Low
*Using the distribution of the ratings, the rating levels were divided into categories of "high" (items rated 3.98 or higher), "moderate", (items rated between 3.97 and 3.13) and "low" (items rated 3.12 or lower).	

Figure 4 compares the average rating of each cluster's importance to facilitating the patient-navigator relationship across the three participant groups through pattern matching. Both patient navigators and patients rated those clusters that dealt with *Empathetic, Comprehensive and Compassionate Support, Bridge to Clinical Education and Supportive Resources and Coordinating Ongoing Individualized Care* as most important to facilitating the patient-navigator relationship, with a high correlation score of $r=0.98$. When compared to administrators, there were slight rating differences observed between patients and administrators as well as patient navigators and administrators, but they were still highly correlated, $r=0.92$ and $r=0.88$ respectively. administrators rated *Coordinating Ongoing Individualized Care* as most important to the patient-navigator relationship followed by *Empathetic, Comprehensive and Compassionate Support and Bridge to Clinical Education and Supportive Resources*. All three groups rated *Skills to Build Trust and Patient Centered Relationships, Personalized Patient Communication and Care and Maintain Professional, Positive and Thoughtful Communication* as less important to facilitating the patient-navigator relationship.

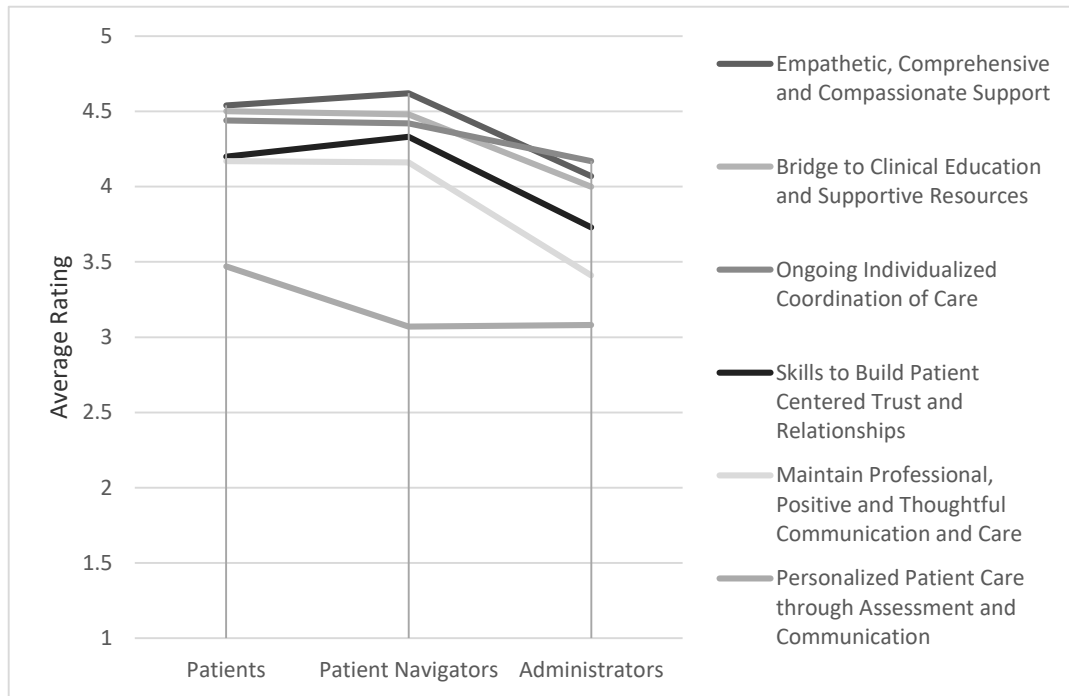


Figure 4. Pattern match of the average rating for the importance of each cluster to the patient navigator relationship across groups.

5.5 DISCUSSION

This study is the first to explore the interpersonal communication components of breast cancer care patient navigation from the perspective of patients with breast cancer, patient navigators and patient navigator administrators. This novel insight was enriched through the high level of stakeholder participant engagement as well as both individual and group level perspectives fostered through the concept mapping data collection, analysis and interpretation process. Furthermore, this study's evaluation of the impact of specific interpersonal communication components on the patient navigator relationship is important to note, as the majority of patient navigation research focuses on clinically focused outcomes. This research identified the

components perceived to be key to interpersonal communication and vital in the promotion of the patient-navigator relationship: *Bridge to Clinical Education and Supportive Resources, Coordinating Ongoing Individualized Care, Empathetic, Comprehensive and Compassionate Support, Skills to Build Trust and Patient Centered Relationships, Maintain Professional, Positive and Thoughtful Communication and Care, and Personalized Patient Care Through Assessment and Communication.*

The identified components included those that had not been studied, or not explored in depth in the existing patient navigation literature. Few studies have examined the components of patient navigation which focus on empathetic and compassionate support and how to build trust and relationships. This study has identified specific and essential aspects of the support and relationship-building skills and behaviors of patient navigators in breast cancer care including not discounting fears and worries, offering genuine care and concern, being courteous and sincere and being a stable contact for patients. In the broader patient navigation literature, qualitative studies have identified the overwhelming and distressing nature of a cancer diagnosis within the complex healthcare system and, similar to this study's results, noted the importance of the patient navigator as a source of stability, comfort and emotional support throughout the cancer care journey (Gunn et al., 2017; Pedersen, Hack, McClement & Taylor-Brown, 2014; Rohan et al., 2016; Rousseau et al., 2014). This emotional support enabled patients to be more engaged in their treatment process, alleviated fears and anxiety, and reduced stress (Gabitova & Burke, 2014; Pedersen et al., 2014; Rohan et al., 2016). The warmth, care, empathy and compassion of the patient navigator was also emphasized (Gabitova & Burke, 2014; Loskutova et al., 2016; Philips et al., 2014). These studies suggested that patient navigators becoming familiar with the patient on a personal level potentially influenced the patient's compliance with treatment (Gabitova &

Burke, 2014). Having the patient navigator as a point person also seems to be a recurrent theme, with one study noting that this created a sense of connection and access to the clinic and was identified as very important to patients (Gabitova & Burke, 2014).

Also identified in this study's findings was the importance of patient navigators connecting patients with clinical education and supportive resources. This is supported in the broader patient navigation literature noting that individualized patient education helped to fill knowledge gaps, allowed patients to ask questions and facilitated informed decision-making (Loskutova et al., 2016; Rousseau et al., 2014). Patients felt this education helped them improve their overall health, emotional health, satisfaction with patient navigation and they felt empowered to participate in their care (Loskutova et al., 2016; Rousseau et al., 2014; Rohan et al., 2016). Pederson and colleagues (2014) found that education support could allay frustration and uncertainty among young women with breast cancer. In a study by Bruan et al. (2012), patient navigators connecting patients to the health system and community resources as well as offering patients and families' education about cancer, was identified by patients as a need throughout the cancer care continuum, from screening through survivorship and end-of-life.

More commonly explored in the patient navigation literature is the role of patient navigators in care coordination and addressing specific patient needs and their potential to reduce health disparities (Escoffery et al., 2015; Gabitova & Burke, 2014; Wells et al., 2017). Gunn et al. (2017) identified that patient navigator programs that were more patient-centered or focused on individualizing care according to the patient's needs and preferences, were most impactful to promoting improved clinical outcomes. These results align with the findings from this study that identify the importance of individualizing care and developing patient-centered relationships. Similar to this study's findings, addressing specific financial barriers for patients is a common and

important task of patient navigators and could potentially lead to more timely cancer care (Gunn et al., 2017; Spencer et al., 2017). Equipping patient navigators with the skills and tools to engage patients in cost discussions is an identified need (Gallups et al., 2017; Gunn et al., 2017; Spencer et al., 2018)

The patient-navigator relationship has been identified as central to patient navigation services as well as a key aspect of patient navigation suggested to produce positive patient outcomes (Jean-Pierre et al., 2011; Philips et al., 2014; Rousseau et al., 2014). Findings from this study demonstrate that the key interpersonal communication components of patient navigation in breast cancer care may also impact the patient-navigator relationship. Those clusters that are perceived to be most important to facilitating the patient-navigator relationship are Empathetic, Comprehensive and Compassionate Support, Bridge to Clinical Education and Supportive Resources and Ongoing Individualized Coordination of Care. Overall, the importance of these components was similar across participant groups, with patients and patient navigators having highly correlated cluster ratings. No substantial differences were found overall between administrators and patients or patient navigators; however, it is important to note administrators found *Ongoing Individualized Coordination of Care* to be most important to the patient-navigator relationship. While there was much similarity between these group in cluster ranking, administrators differed in the perceived degree of importance of each cluster to the patient-navigator relationship, giving each cluster a lower average rating for importance than patients or patient navigators. For example, patients and patient navigators gave the cluster *Bridge to Clinical Education and Supportive Resources* an average rating of 4.50 and 4.48 respectively, while administrators gave this cluster an average rating of 4.00. This difference may be due to the smaller

sample size of administrators as compared to the other participant groups or administrators may be more distant from the relational aspects of the patient navigation process.

The time needed to build and maintain interpersonal communication and relationships in patient navigation has not been adequately addressed. Previous research found that programs that had more real-time, one-on-one interactions between patients and patient navigators or care managers, such as meeting in-person or talking on the phone, produced timely diagnostic resolution at a higher rate, had fewer hospital admissions and less medical expenditure (Gunn et al., 2017; Nelson, 2012). However, there is a lack of evidence to show the “dose” of the patient navigation intervention that is needed to produce positive benefits to patients, such as improving the timeliness of care. Research in behavioral health and therapeutic relationships emphasizes that the relationship between the patient and the provider requires long-term, sustained and frequent interactions as well as the importance of the initial relationship formation during the first few encounters where rapport, trust and confidence is developed (Ardito & Rabellino, 2011; Epstein & Street, 2007; Kornhaber, Walsh, Duff & Walker, 2016; Scott et al., 2008; Zugai et al., 2015). Yet, the relationship between patients and providers may not be a direct function of time, it may be the consistency of the relationship. This study’s findings noted the importance of consistent follow-up by the patient navigator through the *Coordinating Ongoing Individualized Care* cluster, but also the need to check in at specific timepoints during treatment or during times of transition (Pedersen et al., 2014.) This need for a longitudinal relationship is important to note in the planning of a quality navigation program.

There are several limitations in our study. As in all qualitative research, generalizability to other populations and regions is limited. This study had a small sample size and study eligibility criteria limited participation to those with an experience in breast cancer and residing in Western

Pennsylvania. The results of this study will be strengthened by future studies conducted with a larger, more geographically dispersed sample. While this study included a wide range of participants based on demographic variables, we did not include individuals who were non-English speakers.

These findings have both research and practice implications. While the analysis of the data demonstrates only slight differences between groups, it will be important for research moving forward to better understand the similarities and differences between patients, patient navigators and patient navigator administrators' perspectives on the interpersonal communication components of patient navigation. Furthermore, it will be important for future research to evaluate whether there are differences in the interpersonal skills and behaviors between different types of patient navigator groups (nurse, lay, social worker) (Jean-Pierre et al., 2012). Such data will inform interventions targeting patient navigator training and implementation of navigator programs in diverse settings. Our study also highlights the importance of measuring psychosocial or relational outcomes in patient navigation, in addition to more concrete health indicator outcomes (Fiscella et al. 2011; Gunn et al., 2017; Jean-Pierre et al., 2011). Future quantitative or interventional studies of patient navigation should include measures of the interpersonal relationship and expand beyond those interpersonal skills traditionally addressed to include the components identified as important by key stakeholders in this study (Jean-Pierre et al., 2012).

5.5.1 Conclusion

This study adds to the growing body of literature around the essential interpersonal communication components of patient navigation and how those components impact the patient-navigator relationship. Strong interpersonal communication between patients and patient navigators may be

the key ingredient needed to enable and facilitate other aspects of patient navigation, such as the ability to provide patient-centered care, support informed decision making, have respectful interactions, provide appropriate and timely education and facilitate the delivery of healthcare services. The critical importance of understanding the key interpersonal skills and behaviors of patient navigation and then equipping patient navigators with this knowledge, only increases as patient navigation programs continue to expand outside of oncology to other conditions, populations and countries. Our findings can be used to clarify the role of the patient navigator and serve as an evidenced-based foundation to develop and test training curriculum for patient navigators in interpersonal communication and guide evaluation of patient navigation programs.

6.0 MANUSCRIPT #4: STAKEHOLDER PERSPECTIVES ON IDENTIFIED INTERPERSONAL COMMUNICATION COMPONENTS OF PATIENT NAVIGATION AND THE PATIENT-NAVIGATOR RELATIONSHIP IN BREAST CANCER CARE

6.1 ABSTRACT

Background: Although identified as a key competency domain and needed area of professional development, interpersonal communication in patient navigation is understudied. Moreover, the patient-navigator relationship may be influenced by the interpersonal communication skills and behaviors of the patient navigator. This paper reports on the interpretation step of a concept mapping study, where key stakeholders shared their perspectives on six identified interpersonal communication components of breast cancer care patient navigation.

Methods: This study utilized concept mapping, a community-engaged mixed method approach. Participants completed the following concept mapping activities: brainstorming, sorting and rating and interpretation. Interpretation sessions were separate, live sessions conducted with each participant group either in-person or through web conferencing. The interpretation sessions allowed further examination of six interpersonal communication components of breast cancer care patient navigation identified during the brainstorming and sorting steps. The sessions were led by a facilitator, the PI, and were audiotaped and transcribed.

Results: Six two-hour interpretation sessions were conducted with twenty-one participants including patients with breast cancer, breast cancer patient navigators and patient navigation administrators from Western Pennsylvania. Through a group consensus process, six clusters were named. Participants identified that all the identified components were essential to patient navigation, but the ability to build patient-centered trust and relationships as well as maintain professional communication were the most impactful components of the patient-navigator relationship.

Conclusion: These findings have both identified and operationalized the emerging interpersonal skills and behaviors of patient navigators in breast cancer care. These findings can inform the patient navigation role description, competencies, and the development of curriculum for training and metrics for evaluation.

6.2 BACKGROUND

Patient navigation programs first emerged in the 1990s with the aim of addressing persistent disparities in breast cancer care and survival observed among underserved and minority populations (Freeman, Muth & Kerner, 1995; Meredith, 2013; Whitman, Ansell, Orsi & Francois, 2011). The original patient navigation programs utilized lay navigators and aimed to increase access to screening and facilitate the early diagnosis of cancer among underserved patients (Freeman et al., 1995; Freeman, 2013; Freeman & Rodriguez, 2011). As these programs expanded, patient navigation became defined as “assistance by an individual, either lay or medically trained, who assists patients in identifying and addressing individual and system-level barriers to prevent

attrition from and promote the patient's progression along the cancer care continuum” (Freeman et al., 1995; Jean-Pierre et al., 2011; Meredith, 2013; Vargas, Ryan, Jackson & Freeman, 2008).

Outcomes of patient navigation programs demonstrate improvement in breast cancer care outcomes including increased utilization of mammograms, reduction in time to diagnosis and initiation of treatment, as well as improved satisfaction with cancer care (Battaglia et al., 2012; Dudley et al., 2012; Freund et al., 2014; Hunt et al., 2015; Lee et al., 2013; Markossian et al., 2012; Marshall et al., 2015; Mason et al., 2013; Oppong et al., 2016; Percac-Lima et al., 2013; Shroff et al., 2014; Simon et al., 2015). However, the research is limited due to inconsistencies in the patient navigator intervention, lack of information on the patient navigator characteristics and training, variations in outcome measures and a narrow focus on logistical aspects of the patient navigator intervention (Crane-Okada, 2013; Baik, Gallo & Wells, 2016; Ustjanauskas, Bredice, Nuhaily, Kath, & Wells, 2016). Consequently, patient navigation’s gain in popularity and subsequent widespread rapid adoption leaves many components of patient navigation poorly defined (Robinson-White et al., 2010).

One way to better optimize the patient navigator intervention is to better understand the relational dimensions of patient navigation and the potential of relationship building tasks to influence positive cancer care outcomes (Cohen et al., 2013; Jean-Pierre et al., 2011; Phillips et al., 2014; Rousseau et al., 2014; Yosha et al., 2011). Nevertheless, the patient-navigator relationship has gone largely unexplored in the scientific literature. Moreover, the patient-navigator relationship may be influenced by the interpersonal communication skills and behaviors of the patient navigator. In recent years, national patient navigation leaders and oncology patient navigators identified communication and interpersonal skills as a key competency for patient

navigators and improving communication was noted as a need for professional development (Bail et al., 2016; Lubejko et al., 2016; Pratt-Chapman et al., 2014; Oncology Nursing Society, 2017).

For patient navigation to be an evidence-based intervention, we need to better understand and examine the key components of interpersonal communication. This paper reports on the last step of a concept mapping study, interpretation, where key stakeholders shared their perspectives on the six identified interpersonal communication components of breast cancer care patient navigation through:

- 1) Discussion of the six identified communication components of breast cancer care patient navigation and a group consensus process to develop a name for each cluster.
- 2) Diagraming the relationships between the six interpersonal communication components and the patient-navigator relationship.
- 3) Discussion of action steps for practice and research based on the stakeholders' perceptions of the study results.

6.3 METHODS

6.3.1 Design

This study utilized concept mapping, a community-engaged research method. Concept mapping facilitates active participation of participants throughout the research process including study preparation, data collection, analysis and interpretation (Burke et al., 2005). As a mixed method approach, concept mapping facilitates the examination and complex understanding of the range of

factors, both positive and negative, that impact impersonal communication during breast cancer care patient navigation.

6.3.2 Setting and Sample

A stratified purposive sampling technique was employed to provide heterogeneity and involve a variety of key stakeholders in breast cancer patient navigation including patient navigators, patients, and patient navigator administrators (Kane & Trochim, 2007; Lubjeko et al., 2016). Patients included individuals with a history of working with a patient navigator at any point in the breast cancer care continuum, with navigator communication within the last six months to reduce recall bias. Patient navigators must have worked in breast cancer care patient navigation and could be either medically or non-medically trained navigators (i.e., nurse, social worker, lay person). Patient navigator administrators either supervised or were coordinators of breast cancer care patient navigation programs. For all participants, inclusion criteria included: 21 years or older, the ability to read and write the English language, and have the time and availability to participate in the concept mapping steps.

Following IRB study approval, study participants were recruited from a variety of health systems and networks in Western Pennsylvania from November 2017 to February 2018. Patients recruitment included placing flyers in the oncology clinic at a cancer center in Western Pennsylvania, advertising through a research registry, sharing study information through a local breast cancer support group's social media page as well as a patient navigator at a cancer center in Western Pennsylvania identifying potential study participants. Patient navigators and patient navigator administrators were recruited through sharing study information by email through the

Pennsylvania Patient Navigator Network and at local conferences and meetings and utilizing snowball sampling. Those interested were contacted by phone and screened by the principal investigator (PI).

6.3.3 Data Collection

The structured concept mapping process involves several steps that allow for both data collection and data analysis.

6.3.3.1 Brainstorming. The brainstorming step was conducted asynchronously online by individual participants through the Concept Systems Global Max software. The Concept Systems Global Max software allows all data collection to be conducted online (Concept Systems Incorporated, 2016; Walker, Jones & Burke, 2014). For those participants that did not have regular or reliable access to the internet, alternative routes of participation were offered, including mail or in-person data collection options. Once a participant was screened for eligibility and provided informed consent, the PI provided a unique username and password for the online system. Participants could then login and respond to a demographic questionnaire regarding their age, level of education, race/ethnicity, income and years of patient navigation experience (the latter for patient navigators and administrators only). Participants then responded to a focus prompt developed in collaboration with a breast cancer research advisory group. The prompt stated, “Please tell me from your experience, what things, both good and bad, a patient navigator says or does during personal communication (e.g., email, phone, face-to-face conversations) that may impact a patient during their cancer care.” The resulting generated statements were combined into

a master list of unique statements through idea synthesis by the PI and two additional researchers (Kane & Trochim, 2007). This master list was utilized in the subsequent sorting and rating activities.

6.3.3.2 Sorting and Rating. During the sorting step, participants individually sorted the statements on the master list into piles based on their perceptions of similarity among the statements and assigned a label for each pile (Kane & Trochim, 2007). This step was also completed online through the Concept Systems Global software. Participants rated each of the statements on the master list on a scale of 1 to 5 on three scales. Participants rated the statements based on their degree of importance to the patient-navigator relationship, the strength of the perceived relationship between each item and adherence to the provider's recommendations and the degree to which each item impacted satisfaction with cancer-related care (Fiscella et al., 2011; Oncology Nursing Society, 2017).

6.3.4 Data Analysis

6.3.4.1 Core Analysis. The core analysis produces the final concept map. First, a pooled similarity matrix was produced which illustrates the number of participants who sorted each pair of statements together (Burke et al., 2005, Kane & Trochim, 2007). Next, through nonmetric multidimensional scaling of the pooled similarity matrix, each statement was positioned as a point on a two-dimensional map, or point map (Davison, 1983; Kane & Trochim, 2007; Kruskal & Wish, 1978). Then, hierarchical cluster analysis divided the statement points on the point map into non-overlapping clusters utilizing Ward's algorithm, which minimizes the sum of squares of the

distance between statement points (Burke et al., 2005; Everitt, 1980; Kane & Trochim, 2007). The potential cluster solutions were evaluated by the PI and an additional researcher to determine the final concept map.

6.3.4.2 Interpretation Sessions. The interpretation sessions were conducted as multiple, separate, live sessions with each participant group (patients, patient navigators, administrators) and allowed participants to see how their individual ideas contributed to the research process (Kane & Trochim, 2007). The interpretation sessions were conducted in-person for patients and patient navigators and through web conferencing for administrators. Each of the sessions was led by a facilitator (the PI) and an additional researcher who was present to take notes. The goal of the interpretation sessions was to: 1) create a name for each of the six clusters, 2) diagram the relationship between clusters and the patient-navigator relationship and 3) discuss potential action steps based on the study results. Each session began with an overview of the agenda and a review of the concept mapping steps. The resulting point map and concept map from the core analysis were presented and explained to the group. Next, the group worked cluster-by-cluster to read through the set of statements for each cluster and discussed common themes. Then, moving through the list a second time, participants came up with a label for each cluster as a group. To promote group consensus, each subsequent group utilized the label created in the previous session. If there was disagreement, the facilitator encouraged the group to use a hybrid name, perhaps by combining titles. Participants also worked as a group to diagram the relationship between clusters and to the patient-navigator relationship utilizing large sheets of paper and markers (Albert & Burke, 2014). Additionally, the facilitator engaged the participants in a discussion about future action steps based on the study results (Albert & Burke, 2014; Burke et al., 2005). Each of the sessions were audiotaped and

transcribed. Transcripts and written notes from each interpretation session were reviewed to ensure accurate documentation of participant comments.

6.4 RESULTS

The brainstorming step generated 121 non-unique items from 24 participants (10 patients, 10 patient navigators, 4 administrators) in response to the focus prompt. These items were synthesized into a master list of 85 statements by two researchers and the PI. Twenty-four participants (10 patient navigators, 10 patients and 4 administrators) sorted and rated the 85 statements. The core analysis resulted in a six-cluster concept map (see Figure 3).

Six interpretation sessions were conducted to interpret the six-cluster concept map (3 with patients, 2 with patient navigators and 1 with administrators). The sessions consisted of small groups of two to five participants and lasted approximately 2 hours each. A total of 21 participants participated (10 patients, 9 patient navigators and 2 administrators). See Table 5 for participant characteristics.

Table 5. Demographics according to participant group.

Variable	Patients (n=10)	Patient Navigators (n=9)	Administrators (n=2)
	Mean ± SD		
Age	57.60 ±9.49	39.22 ±10.07	61.50 ±2.12
Years Patient Navigation Experience	N/A	3.11 ± 2.759	15.00 ± 0.00
	N (%)		
Race/Ethnicity			
White or Caucasian	5 (50%)	8 (88.9%)	2 (100%)
Black or African American	5 (50%)	1 (11.1%)	0 (0%)
Hispanic, Latino or Spanish origin	0 (0%)	0 (0%)	0 (0%)
Asian	0 (0%)	0 (0%)	0 (0%)
Other	0 (0%)	0 (0%)	0 (0%)
Education			
Elementary School or Less	0 (0%)	0 (0%)	0 (0%)
Some middle or junior high	0 (0%)	0 (0%)	0 (0%)
Some high school	0 (0%)	0 (0%)	0 (0%)
High school graduate (diploma, GED, or equivalent)	0 (0%)	0 (0%)	0 (0%)
Some college or technical school	7 (70%)	0 (0%)	0 (0%)
Associates degree	1 (10%)	0 (0%)	0 (0%)
4-year college degree	2 (20%)	5 (55.6%)	2 (100%)
Master's, Professional or Doctoral degree	0 (0%)	4 (44.4%)	0 (0%)
Income			
\$24,999 or less	6 (60%)	0 (0%)	0 (0%)
\$25,000 to \$34,999	2 (20%)	0 (0%)	0 (0%)
\$35,000 to \$49,999	0 (0%)	2 (22.2%)	1 (50%)
\$50,000 to \$74,999	1 (10%)	1 (11.1%)	0 (0%)
\$75,000 or more	1 (10%)	6 (66.7%)	1 (50%)

6.4.1 Naming and Discussion of the Six Clusters

Through the group consensus process, a final name was determined for each of the six clusters and the discussion identified both core elements and areas of disagreement within each cluster across the participant groups (See Table 6).

Table 6. Stakeholder perspectives of each of the six components of interpersonal communication in breast cancer care patient navigation.

Cluster	Commonly Agreed Upon Elements
Empathetic, Comprehensive, Compassionate Support	<ul style="list-style-type: none"> • These are core skills for a patient navigator. • Emotional support is a core element of patient navigation. • Support should be comprehensive and extend to the patient's family. • Patient navigator communication should demonstrate compassion across the board. • Empathy is a key element of patient navigator support.
Bridge to Clinical Education and Supportive Resources	<ul style="list-style-type: none"> • The patient navigator should be resourceful and have clinical expertise. • Resources should include both clinical resources as well as emotional support resources. • These resources should be offered to both patients and families. • Patient navigators can be a bridge to hidden resources or those resources that are difficult to access, such as financial resources.
Ongoing Individualized Coordination of Care	<ul style="list-style-type: none"> • Coordination of care is a main task of patient navigation as it can help reduce stress and burden for the patient. • Care coordination must be individualized to address specific patient needs. • Care coordination should be ongoing across the care continuum.
Skills to Build Trust and Patient Centered Relationships	<ul style="list-style-type: none"> • These are basic skills for all patient navigators. • The patient navigator needs to be patient-centered. • Good bedside manner and kind gestures are essential for relationships and trust. • The patient navigator should exhibit positivity. • Relationship-building is the starting point for patient navigators.
Personalized Patient Assessment and Communication	<ul style="list-style-type: none"> • Assessment and communication are essential tools for identifying individual barriers to care. • Requires familiarization with patient and attention to detail.
Maintain Professional, Positive and Thoughtful Communication and Care	<ul style="list-style-type: none"> • Patient Navigators need to understand patient preferences. • Clear and transparent communication are needed to avoid misunderstanding. • Professional behavior is essential during the initial interactions between the patient and patient-navigator and must be maintained throughout.

6.4.1.1 Empathetic, Comprehensive and Compassionate Support. All the groups felt this cluster at its core was focused on the empathetic and emotional support offered by the patient navigator, with one administrator noting, “I don’t want to lose the empathetic component of this, because I think that is crucial to navigation.” Patient navigators noted the importance of that support being reliable, consistent, open and accepting. The comprehensive component was eventually added to the name to recognize that support offered by the patient navigator should be all encompassing and extend to the patient’s family. This element was emphasized by one navigator who stated, “I really take care of the patient and their family from all areas. So, we’re talking clinically, we’re talking outside of the clinical setting, offering support in many different ways.” Comprehensive support was also an important element to patients with one patient noting, “The phrase comprehensive comes to view for me because this takes in not just the patient, but the patient’s family, and also recognition that the care from the navigator may change over time as the patient’s emotional and acceptance level changes.” Compassion at every stage was also considered a core element of this cluster.

6.4.1.2 Skills to Build Patient Centered Trust and Relationships. Many participants felt this cluster described how patient navigators interact with the patient and their general bedside manner, such as offering kind gestures. Similar to Empathetic, Comprehensive and Compassionate Support, participants identified this cluster as basic skills needed by all patient navigators. One patient mentioned, “Like always being courteous and polite, always having good eye contact, being aware of nonverbal communication, sit at their level, be comfortable with silence and tears. That seems to be just readily understood if you are a patient navigator and you have a background in social work or psychology or nursing or whatever.” All participants agreed that this cluster

focused on building trust and relationships; however, there was discussion over whether these are characteristics or skills. One patient navigator noted, “You can teach skills, while characteristics, it feels like those are already there.” Patient-centered was also added to the cluster name because both patient navigators and administrators noted this descriptor as key to the ability to build relationships and trust with patients. Patient-centeredness included being both reliable and available to the patient. Patients emphasized the importance of positive interactions and the patient navigator exhibiting positivity. One patient noted, “The more you [the patient navigator] give ‘em life and talk upward, the more a person feels they can survive and kick this thing in the butt.”

One participant acknowledged particular items that might differ for those with Stage 4 breast cancer and the need to be sensitive to issues of mortality. She noted her disagreement with statements focusing on offering assurance that everything will work out and describing cancer treatment as having an “end”. The participant mentioned, “But if you have Stage 4 diagnosis, everything is not going to work out.”

6.4.1.3 Bridge to Clinical Education and Supportive Resources. For many participants the role of the patient navigator was increase access to and awareness of available resources. One patient noted, “They [patient navigators] are the bridge to get you there.” It was also emphasized that these resources include supportive resources, such as support groups and other types of emotional support, in addition to clinical education. Patients expressed the importance of patient navigators connecting them with resources to support their decision-making as well as difficult to access resources, such as financial resources. One patient mentioned, “Without them [patient navigator], you wouldn’t know it was out there.” For patient navigators and administrators, this cluster focused on the resourcefulness and clinical expertise of the patient navigator. These activities included

offering good advice, providing educational support and making resources available, such as community resources. This also extended to family members. One patient mentioned, “My husband was having some difficulty, and unbeknownst to me, he contacted the patient navigator, and [the navigator] sent a book out to him about how families cope with a person in their immediate family who has been diagnosed.”

6.4.1.4 Ongoing Individualized Coordination of Care. For all participants, this cluster described a main task for patient navigators: advocating for patients and coordinating care. One patient mentioned, “Someone walking you through it [cancer care], that’s the best medicine in the world.” A patient navigator noted, “I think they want that care coordinated, because you’re taking that out of their hands and making sure everything is in place for them to get good treatment, and that’s a big load off of them, because they are overwhelmed to begin with and helping them get through that whole process in the beginning is, I think, is very important for them.” Another key aspect to this cluster was the individualization of the care coordination. One patient said, “Depending on the person’s need would depend on how the navigator guided their options for them. Like losing hair, I wasn’t worried about losing my hair, I was worried about losing my eyebrows.” Patient navigators and administrators also described the coordination of care as both ongoing, or across the breast cancer care continuum, and multidisciplinary. One patient navigator mentioned, “I like ongoing coordination of care, because you know, we’re talking about the work that we do and we’re coordinating with other providers in the community.” While not included in the cluster name, both patients and patient navigators pointed out the individualized coordination of care increased the patient’s confidence and the comfort with the health care system staff and their cancer care. One patient also noted care coordination helped to reduce stress while she was focused

on her cancer diagnosis by saying, “The pressures that you would normally have, your family would have. She [patient navigator] took those pressures away.”

6.4.1.5 Personalized Patient Care through Assessment and Communication. Building from both the *Bridge to Clinical Education and Supportive Resources* and *Ongoing Individualized Coordination of Care*, participants felt this cluster described additional support measures offered by patient navigators to address specific patient needs. Participants agreed this cluster described ways patient navigators used communication to assist with daily breast cancer care and required familiarity with the patient and attention to detail. Patient navigators mentioned the importance of anticipating a patient’s needs and being proactive. Eventually, assessment and communication were added to the cluster name to identify how these tools allowed the patient navigators to identify and address specific patient needs, with one patient navigator noting, “You have to individualize [care] based off your assessment and communication.” Similar to *Building Patient Centered Trust and Relationships*, one patient noted that an overwhelmed navigator may not be able to do all of these tasks for a patient.

Disagreements did arise in the discussion of this cluster. At first, patients saw this cluster as describing a phenomenal patient navigator that went “above and beyond”. One patient mentioned, “Well that’s so above and beyond. To take time out of your day to help someone get a ride someplace.” However, patient navigators and administrators pointed out that these are standard practices of patient navigators with one patient navigator mentioning, “But it’s not above and beyond, I disagree with the statement too, I think it’s just the job. I think it’s just giving help in whatever way they need.” Several patients disagreed with the role of patient navigators sharing pathology results. They stated their preference for the patient navigator to help them interpret

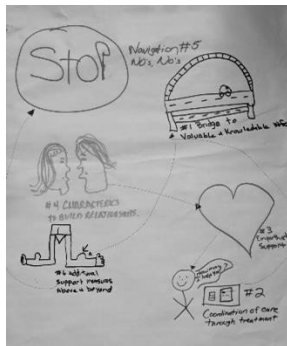
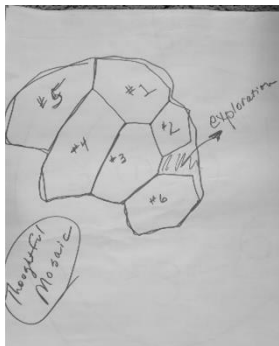
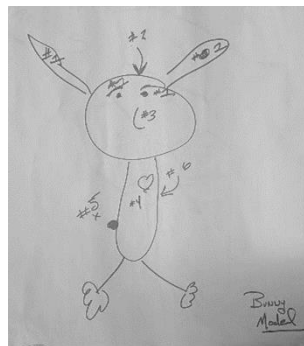
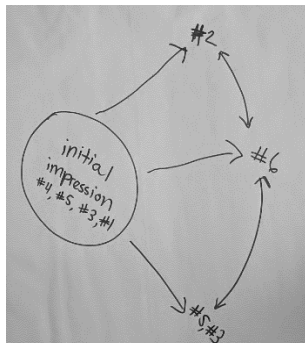
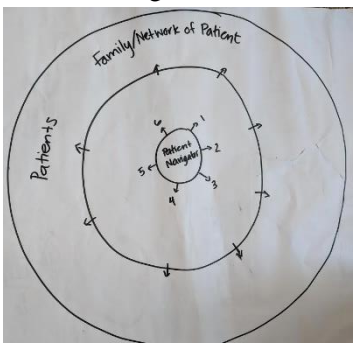
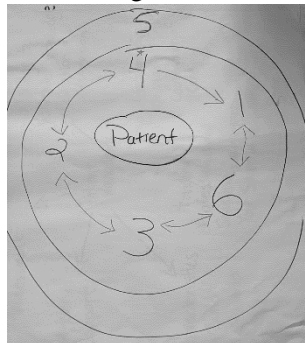
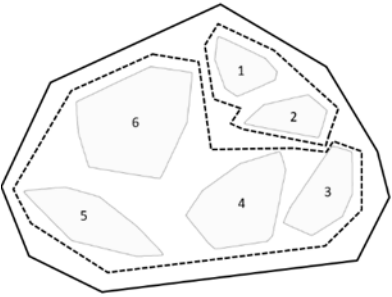
results not provide the results. One patient noted, “I would not want to hear it from anyone but the person who is treating me. I don’t want to hear it from a third party.”

6.4.1.6 Maintain Professional, Positive and Thoughtful Communication and Care. This cluster began with discussions of what actions patient navigators should avoid. One patient mentioned, “I would call these bad practices to avoid because they are, particularly this last one, I know how you feel. No, you don’t. They can be compassionate and understanding, but I think until you walk in somebody’s shoes, you shouldn’t say that.” Discussion of this cluster transitioned to the importance of professionalism by patient navigators and providing sensitive care. Maintain was added to the cluster title to identify that professionalism is ongoing. One administrator pointed out, “It just implies that no matter what, you’ve got to keep on maintaining. As close as you may get...what you need to do is still maintain your professional demeanor.” Positive and thoughtful were also added to the title to further clarify the importance of remaining positive and being mindful of patient preferences. Patients agreed that avoiding misunderstandings and not “leading patients on” about what’s possible were essential to maintaining professional communication.

Patients commonly acknowledged their disagreement with the statement “do not discuss politics or religion.” Patients emphasized the need to be able to talk about their faith and religion as part of their care noting, “They have to be careful to personalize us and not lump us all together. If a person wants to be religious, then go there with them.” Another patient mentioned, “I think a lot of patients turn to religion in this kind of situation. That doesn’t work for me, but I think they [patient navigator] need to be independent of how they feel, I think they need to be receptive to talking about people’s beliefs.”

6.4.2 Relationships Between Clusters and the Patient-Navigator Relationship

In each of the six sessions, participants worked together to draw a diagram or multiple diagrams to describe how each of the six clusters related to one another and to the patient-navigator relationship. The images that were created are shown in Figure 5.

<p>A. Patients</p> 	<p>B. Patients</p> 	<p>C. Patients</p> 
<p>D. Patients</p> 	<p>E. Patient Navigators</p> 	<p>F. Patient Navigators</p> 
<p>G. Administrators</p> 	<p>1 = Bridge to Clinical Education and Supportive Resources 2 = Ongoing Individualized Coordination of Care 3 = Empathetic, Comprehensive and Compassionate Support 4 = Building Patient Centered Trust and Relationships 5 = Maintain Professional, Positive and Thoughtful Communication and Care 6 = Personalized Patient Care through Assessment and Communication</p>	
<p>A. Patients identified that the first step for the patient navigator is the development of the relationship and trust between the patient and patient-navigator. The patients felt that once the trust and relationship are established, the patient navigator is able to offer the Empathetic, Comprehensive and Compassionate Support. Next, the patient navigator can begin the Ongoing Individualized Coordination of Care, be a Bridge to Clinical Education and Supportive Resources and provide Personalized Patient Care through Assessment and Communication. However, the patient navigator needs to avoid certain actions identified in the Maintain Professional, Positive and Thoughtful Communication and Care cluster.</p> <p>B-C. The second group of patients created two images to represent the relationship between clusters. The first figure is a brain and the second took the form of a rabbit. In these two figures, the patients described all the clusters as significant and necessary for good patient navigation. They all have a different function and complement one another. Patients saw the trust and relationship between the patient and patient navigator as the most important element, in Box C it is the heart of the rabbit.</p>		

D. The patients agreed that all the clusters are essential. The patients also noted that initial impression feeds into ongoing tasks of the patient navigator, including the Ongoing Individualized Coordination of Care, Personalized Patient Care through Assessment and Communication. They also emphasized that both Maintain Professional, Positive and Thoughtful Communication and Care and the Empathetic, Comprehensive and Compassionate Support are ongoing pieces that continually feed into the patient-navigator relationship.

E. The first patient navigator group emphasized that each cluster was part of the patient navigator role without order of importance.

F. The second patient navigator group felt the patient was the center focus and emphasized the importance of the initial interaction where the patient navigator begins to build trust. From that initial interaction, the patient navigator is able to provide education and resources as well as assess the patient's needs. They can also provide support and care coordination. These clusters are ongoing and fluid and are dependent on the patient's particular situation. However, each of these clusters feeds into the patient-navigator relationship. They also felt that Maintain Professional, Positive and Thoughtful Communication and Care was overarching and influenced the whole process.

G. In this image (Figure G), both Bridge to Clinical Education and Supportive Resources and Ongoing Individualized Coordination of Care were main tasks of patient navigators or part of the job description. The remaining clusters are the elements that enable patient navigators to accomplish these tasks.

Figure 5. Diagrams of relationships between six clusters and the patient-navigator relationship.

6.4.2.1 Patient Perspectives. Patients described each cluster as a piece of a puzzle, all were essential parts of the interpersonal communication between patients and patient navigators and in combination, resulted in better cancer care. The three patient groups also emphasized *Empathetic, Comprehensive and Compassionate Support* as well as *Skills to Build Trust and Patient Centered Relationships* as the core or foundation to build the patient-navigator relationship. Additionally, one patient group focused on the importance of the initial first impression between the patient and the patient navigator. That initial impression is impacted by the clinical education, knowledge and resources provided by the patient navigator, their empathetic and compassionate support, their ability to develop trust and build relationships as well as their professionalism. One patient noted, “If you’re not professional, you can throw all the other things [clusters] out. If you come to me and you’re not professional, positive and thoughtful, I’m not listening to nothing you have to say.”

6.4.2.2 Patient Navigator Perspectives. The patient navigator groups emphasized that all the clusters, despite their importance, are required in order to provide holistic care and promote a better patient-navigator relationship. These groups also noted that each cluster individually promotes a better relationship, but they also interact with one another to improve outcomes. One patient navigator mentioned, “Each cluster is connected to the others and they build off each other and where you start may depend on the patient’s needs.” Some of the patient navigators did note the importance of the initial interaction and the ability to establish the relationship and trust in the beginning by saying, “I think first you have to build that trusting relationship for everything else can come into play.” Patient navigators also felt that *Maintain Professional, Positive and*

Thoughtful Communication and Care was key throughout the patient navigation process and influenced the ability to develop and maintain the patient-navigator relationship.

6.4.2.3 Administrator Perspective. The administrators also emphasized that each of the six clusters relate back to the patient-navigator relationship. One administrator mentioned, “It’s all about the relationship with the patient, and navigation is really all about building relationships throughout the whole thing.” Administrators noted that clusters including *Bridge to Clinical Education and Supportive Resources*, *Ongoing Individualized Coordination of Care*, and *Personalized Patient Care Through Assessment and Communication* represented the main tasks of patient navigation. The remaining clusters, *Empathetic, Comprehensive and Compassionate Support, Maintain Professional, Positive and Thoughtful Communication and Care* and *Skills to Build Trust and Patient Centered Relationships* are the components that facilitate the effectiveness of the main tasks.

6.4.3 Identified Action Items

Each interpretation session also discussed potential action steps and utilization of the six clusters.

Across the three participant groups, there were some common action items identified.

- Providing training for patient navigators was commonly agreed upon as an important next step based on this study’s results for both new and experienced patient navigators.
- Patient navigators identified the need for networking and a place to share resources among patient navigators.

- Patients and patient navigators identified the need to increase awareness of patient navigation services and their role. Patients also noted the importance of disseminating information regarding the value of patient navigation, such as sharing this information with health system administrators, and better incorporating patient navigators into the clinic visit. Patient navigators identified the importance of increasing awareness among healthcare providers about the role of patient navigators in oncology care.
- Administrators, patient navigators and patients identified that we need a better understanding of the key components of patient navigation for unique patient populations including: the homeless, non-English speakers, patients with mental health issues or younger women with breast cancer.

6.5 DISCUSSION

This study reports on key stakeholder perspectives and group consensus on six identified components of interpersonal communication in breast cancer care patient navigation. Prior to this study, the specific interpersonal aspects of breast cancer care patient navigation have never been explored in-depth using a community-engaged approach. Interpersonal communication components of patient navigation clearly impact the amount of support felt by the patient, as well as the ability of the patient navigator to connect patients to education and resources, coordinate care, identify and address individual patient needs and build trusting, patient-centered relationships.

These findings demonstrated the importance of building patient centered trust and relationships between patients and patient navigators from the perspective of key stakeholders in

breast cancer care. The importance of establishing a trusting relationship with the patient navigator aligns with the broader patient navigation literature (Carroll, Humiston, Meldrum, Salamone, & Jean-Pierre, 2010; Feather, Carter, Valaitis & Kirkpatrick, 2017; Gotlib Conn, Hammond Mobillio, Rotstein, & Blacker, 2016). This study, through the process of facilitating group consensus, identified that in most cases building trust and establishing a relationship was not only essential but also was the first step for patient navigators. Furthermore, the ability of patient navigators to develop these relationships and trust are skills that need to be taught and supported, not assumed. Specific traits of the patient navigator that were discussed as important to the relationship were being reliable, available and positive.

Consistently, the importance of maintaining professionalism was raised as a key element to both interpersonal communication and the patient-navigator relationship. Professionalism from the standpoint of the interaction between patients and patient navigators has not been discussed in the broader patient navigation research but was clearly identified as the keystone to interpersonal communication in patient navigation and possibly the larger patient navigation model by this study's participants. While these skills and behaviors may be expected of all health care professionals, it will be important to ensure that patient navigators, who have a variety of different medical and non-medical backgrounds, are trained and supported in their ability to interact with patients in a professional, positive and thoughtful way. In particular, patients identified the importance of patient navigators being willing and able to approach conversations of faith as part of a patient's cancer care journey. Patient navigators could benefit from skill building and resource sharing to not only support their cultural sensitivity but also their ability to have discussions of patient's spirituality or religion (Willis, Hoffer, Villalobos & Pratt-Chapman, 2016).

The diagrams generated by the study participants provided insight into the nature of the relationships between the six identified interpersonal communication components and the patient-navigator relationship. Similar to the broader patient navigation literature, this study's participants also identified the key role of the patient-navigator relationship and its potential to facilitate and optimize the main tasks of patient navigation (Feather et al., 2017; Jean-Pierre et al., 2011; Philips et al., 2014). The development of a therapeutic patient-navigator relationship needs to be included in patient navigator program models. However, quantitative evidence is lacking to support the patient-navigator relationship's association with cancer care outcomes as well as a valid instrument to measure the patient-navigator relationship.

This patient-navigator relationship may be impacted by patient navigators who are overwhelmed with a large caseload. Patient navigators report a wide range of average annual caseloads with some having fewer than a hundred and others more than 400 (Howard, Freund & Battaglia, 2010). Patient navigation research needs to identify and better understand the appropriate caseload for a patient navigator, especially as patient navigator caseload may not reflect the patient navigator's workload and may depend on where the patient is on the care continuum (Howard, Freund & Battaglia, 2010). While complex, the patient navigator caseload has the potential to impact the patient-navigator relationship and subsequently, cancer care outcomes (George Washington Cancer Institute, 2013).

In this study, group consensus through the concept mapping process elucidated actionable items with both practice and research implications. Training for patient navigators as well as providing general practice resources and networks to share experiences are a crucial need for both new and experienced patient navigators. Furthermore, there is a need to increase awareness of the patient navigator role and how they function as part of the health care team. Patients expressed a

desire to increase knowledge of the availability, importance and benefits of patient navigation among patients and health system administrators. There is also a need to further delineate the key aspects of patient navigation for higher risk patient populations.

6.5.1 Strengths and Limitations

A strength of the concept mapping process is the high level of participant inclusion, which ensures that the results reflect both individual and group perspectives on the relationships between the interpersonal communication components of breast cancer care patient navigation and the patient-navigator relationship. While this study included participants from multiple health systems and organizations as well as both rural and urban settings, limiting the inclusion criteria to Western Pennsylvania and the small sample of patient navigator administrators could limit the generalizability of this study's findings. Although the decision to keep the three participant groups separate for the interpretation sessions was made to reduce power dynamics, it could be a limiting factor to the overall group consensus process. The separate interpretation sessions produced multiple different diagrams making it difficult to select a final model to represent the relationships between the clusters and the patient-navigator relationship. Future studies should confirm this study's findings in a larger geographic region and with a more diverse study population.

6.5.2 Conclusion

This study contributes new knowledge about the interpersonal communication components of breast cancer care patient navigation that may be essential to promoting positive cancer care

outcomes. These findings have the potential to contribute to the operationalization and measurement of interpersonal skills and behaviors of patient navigators in breast cancer care. These findings can serve as an evidence base to inform the patient navigation role description, competency development, curriculum for training and as metrics for evaluation.

APPENDIX A

PERMISSION LETTER AND PRELIMINARY WORK MANUSCRIPT #1

Sarah F. Gallups
University of Pittsburgh
School of Nursing
3500 Victoria Street
Pittsburgh, PA 15261

June 14, 2018

Kristin Siyahian
Editorial Director
Journal of Oncology Navigation and Survivorship
PO Box 563
Cranbury, NJ 08512

Dear Ms. Siyahian:

This letter will confirm our recent e-mail exchange. I am completing a doctoral dissertation at the University of Pittsburgh entitled "Identifying the Interpersonal Communication Components of Breast Cancer Care Patient Navigation." I would like your permission to reprint in my dissertation excerpts from the following:

Gallups, S. F., Connolly, M., Simon, J., & Rosenzweig, M. Q. (2016). Quantifying the relational dimensions of study staff in a randomized control trial among African American women recommended to receive breast cancer chemotherapy. *Journal of Oncology Navigation and Survivorship*, 7 (11), 27-35.

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If these arrangements meet with your approval, please sign this letter where indicated below and return it to me. Thank you very much.

Sincerely,



Sarah Gallups, RN, BSN, MPH

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE:

Kristin Siyahian

Digitally signed by Kristin Siyahian
DN: cn=Kristin Siyahian, o=au,
email=kjsyahian@sanr.com, c=US
Date: 2018.06.14.14:46:30 -0700

Kristin Siyahian, Editorial Director

Date: 6-14-18

Quantifying the Relational Dimensions of Study Staff in a Randomized Controlled Trial Among African American Women Recommended to Receive Breast Cancer Chemotherapy

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Background: The Adherence, Communication, Treatment, and Support (ACTS) randomized controlled intervention study was a one-time psychoeducational intervention encouraging adherence of African American women to prescribed chemotherapy. Surprisingly, 98% of both the intervention and usual care groups initiated chemotherapy.

Objective: This study is a secondary aim of the ACTS intervention study to explore the influence of nonspecific factors of a largely racially concordant study team on study outcomes in the usual care group and compare the results with previously obtained debriefing questionnaire data from the ACTS intervention group.

Methods: An investigator-derived debriefing questionnaire was completed in both groups regarding non-specific factors such as support, bond, and concern displayed by the ACTS study team or the interventionist. Descriptive statistics and independent *t* tests were used to analyze subscores and compare total scores of both groups.

Results: The nonspecific factors of concern for health and well-being ($n = 32$, $M = 11.41$ in usual care; $n = 50$, $M = 11.02$ in intervention) and support ($M = 11.38$ in usual care, $M = 10.74$ in intervention) were ranked highest in both groups. While the usual care group had higher mean scores overall, the mean subscores and total score ($P = .4$) between the groups were not significantly different.

Discussion: Regardless of intervention, all women felt a sense of support. These elements of support from study staff as well as a racially sensitive intervention may have encouraged adherence and contaminated study findings.

Conclusion: The results from this study points to the need for health disparity researchers to evaluate the impact of nonspecific factors in intervention research.

Both nationally and locally there is a disparity among African American women for initiation of recommended chemotherapy for breast cancer. As a response to this disparity, researchers at the University of Pittsburgh School of Nursing developed and tested a randomized controlled trial of a psychoeducational intervention for African American women to encourage understanding of why chemotherapy was recommended, and to address fears and concerns related to therapy. The Adherence, Communication, Treat-

ment, and Support (ACTS) intervention was developed in an iterative fashion with the assistance of a community-based African American breast cancer survivor organization.¹ At the recommendation of the community advisory group, the research staff interacting with the participants was almost entirely African American. Through the use of tailored decision-making tools and a race-matched interventionist, the ACTS intervention addressed attitudes that may impact the decision to accept chemotherapy, promoted

patient communication with healthcare providers, provided tailored health information about breast cancer treatment, and offered support through the presence of an African American breast cancer survivor interventionist and tailored video messages from the African American community.¹ The one-time intervention was 30 to 45 minutes in duration.

Participant enrollment concluded in September 2014. Interestingly, 97.1% (N = 69) of the usual care group and 98.5% (N = 69) of the ACTS intervention group initiated chemotherapy. This surprising result was then analyzed according to the nonspecific factors that may have influenced the results of this trial.

Nonspecific factors are a key element to consider when examining research outcomes. These factors may not be specified by theory or by the study purpose but may influence study outcomes.

Nonspecific factors are a key element to consider when examining research outcomes. These factors may not be specified by theory or by the study purpose but may influence study outcomes.^{2,4} This is in contrast to specific factors that are “essential, theoretically derived components of the intervention” expected to produce the desired change in the dependent variable.⁵ Nonspecific factors in a research study, more specifically randomized controlled trials, may be a result of the participant-interventionist relationship. The formation of that relationship may be influenced by the similar background or life experiences of the participant and interventionist, and the bond that forms may affect the participant’s response to the intervention.^{6,7} In addition to the bond, the presence of other nonspecific factors may include the participant’s motivation to please, the participant’s outcome expectations, interventionist qualities (eg, warmth, positive regard, competence), and attention bestowed on the participant.^{3,5}

These nonspecific factors may become even more apparent in health disparity research due to the necessity of these studies to tailor and design culturally relevant interventions. Furthermore, these nonspecific factors may come into play during the recruitment, intervention, or data collection. For example, if the disparity is race-based, an effort to create an atmosphere conducive to the enrollment of minority individuals by using race-matched recruiters could also produce the

desired change in the dependent variable. Additionally, common ways for African American women to support one another and cope with a breast cancer diagnosis is through spiritual interventions such as prayer; this nonspecific factor is not part of the intervention protocol, and it may influence the participant’s receptiveness to the intervention.⁸⁻¹¹ Nonspecific factors present in randomized controlled trials of health disparity interventions have not received adequate attention despite their ability to muddle the effects of theoretically derived intervention components. Therefore, it is imperative that researchers identify and quantify the effects of nonspecific factors in randomized controlled trials of psychoeducational interventions to accurately distinguish those effects from the efficacious components of the intervention.⁵

Objective

The present study is a secondary analysis from the ACTS intervention study aiming to explore the influence of nonspecific factors of a largely racially concordant study team on study outcomes in the usual care group and compare the results with previously obtained debriefing questionnaire data from the ACTS intervention group. The study protocol was approved by the University of Pittsburgh Institutional Review Board.

Methods

Participants

Participants included women recommended to receive chemotherapy between January 2011 and June 2015. Individuals were eligible to participate in the ACTS intervention study if they self-reported black race, were aged 18 years or older, had been diagnosed with invasive breast cancer at any stage, and were recommended to receive chemotherapy. Individuals were excluded if they had impaired cognition (measured by a score of less than 22 on a Mini Mental Status Exam) and were not able to understand the English language. Individual eligibility was confirmed by clinician verification that the patient was recommended to receive chemotherapy. Informed consent was obtained from all study participants. Study participants were recruited from 6 cancer centers located in western Pennsylvania and northeast Ohio.

Measurements

Sociodemographic Factors: Sociodemographic factors were measured using an investigator-derived Sociodemographic Questionnaire, a 23-item form that includes variables such as age, marital status, employment status, household composition, health insurance status, and income level.

The debriefing questionnaire was the mechanism for examining the effect of nonspecific factors (ie, bond, motivation to please, attention, and interventionists' supportive behaviors) on outcome measures, including improved adherence and improved scores on 3 proximal outcome measures (follow-through with chemotherapy, overall cancer distress, and social support). The debriefing questionnaire was completed in both the intervention and usual care groups. The questionnaires were administered in person or by telephone for the ACTS group at the completion of the study. The usual care group questionnaires were completed at a later date and by telephone.

ACTS Debriefing Questionnaire: Questions were developed based on previous research delineating supportive components of an intervention or from the interventionist.^{3,5} This questionnaire was investigator-derived and assessed specific components of the ACTS intervention and the overall research methodology (nonspecific effects) that were most meaningful to the ACTS participants in their decision to accept or not accept chemotherapy. The questionnaire utilized a 5-point Likert-type scale with 1 indicating "not at all" and 5 "very much" and a possible point range of 24 to 120, where a higher score indicated a greater influence of the ACTS interventionist. The 24-item questionnaire measured the amount that the suggestions of, tumor and treatment information provided by, support provided by, bond felt with, not wanting to disappoint, time and attention of, and concern for the participant's health and well-being by the ACTS interventionist influenced their follow-through with chemotherapy, level of support felt, and distress level.

Usual Care Debriefing Questionnaire: This questionnaire was investigator-derived and assessed specific components of the overall research methodology (nonspecific effects) that were most meaningful to the usual care participants in their decision to accept or not accept chemotherapy. The questionnaire utilized a 5-point Likert-type scale with 1 indicating "not at all" and 5 "very much" with a possible point range of 15 to 75, where a higher score indicated higher influence of ACTS study staff. The 15-item questionnaire measured the amount the support of, bond felt with, not wanting to disappoint, time and attention of, and concern displayed by the ACTS study staff influenced their follow-through with chemotherapy, level of support felt, and distress level.

Data Collection and Analysis

The study data were collected in interview format through in-person or telephone interviews. The inter-

vention group debriefing questionnaires were completed at time point 3, which corresponded to the end of chemotherapy, between August 2010 and February 2015. Since similar adherence was noted in the groups, the debriefing questionnaires in the usual care group were collected after time point 3 between November 2015 and February 2016. The data were then entered and verified in REDCap (Research Electronic Data Capture), hosted at the University of Pittsburgh.¹² Data management was then conducted using SPSS version 23.¹³ Subscores were calculated for support, bond of shared experience, not wanting to disappoint, time and attention, and concern for health and well-being, as well as sub-

Descriptive statistics were used to summarize the data. Intervention and usual care group subscores and total scores for the matched questions were compared using independent *t* tests.

scales for support, follow-through with chemotherapy, and distress level. Three nonspecific factors were removed from the ACTS intervention group debriefing questionnaire subscores and total score (ACTS Video influence, interventionist suggestions, tumor and treatment information) that were not included in the usual care group debriefing questionnaire. Descriptive statistics (mean, standard deviation [SD]) were used to summarize the data. Intervention and usual care group subscores and total scores for the matched questions were compared using independent *t* tests.

Results

Subject Characteristics

A total of 151 African American women were consented and randomized for study participation from the 6 study sites. The women were randomized to the ACTS intervention group (*n* = 75) or usual care group (*n* = 76). A total of 82 participants in both groups completed the debriefing questionnaire—50 in the ACTS intervention group and 32 in the usual care group (Figure).

Sociodemographic

The majority of participants (*n* = 53, 64.6%) were between the ages of 41 and 60 years, with 6.1% (*n* = 5) 40 years or younger and 29.3% (*n* = 24) older than 60 years. At baseline, 32.9% of participants had never been married, 34.1% were married or partnered, and 32.9%

Table 1 Sociodemographic Variables (N = 82)	
Variables	n (%)
Age at Consent	
≤40 years old	5 (6.1)
41-60 years old	53 (64.6)
>60 years old	24 (29.3)
Current Partner Status	
Never married	27 (32.9)
Married/Partnered	28 (34.1)
Not married or partnered	27 (32.9)
Current Employment Status	
Full-time	34 (41.5)
Part-time (<35 hours)	10 (12.2)
Not working	38 (46.3)
Income Meets Basic Needs	
Yes	54 (65.9)
No	28 (34.1)
Annual Income	
Under \$10,000	11 (13.4)
\$10,000 to \$30,000	23 (28.0)
\$30,000 to \$50,000	13 (15.9)
Over \$50,000	14 (17.1)
Declined to answer	20 (24.4)
Stage of Disease	
Stage 1	32 (22.9)
Stage 2	67 (47.9)
Stage 3	23 (16.4)
Stage 4	12 (8.6)
Unknown	6 (4.3)

were not married or partnered. Regarding work, 41.5% (n = 34) of the participants had full-time employment, 46.3% (n = 38) were not working, and 12.2% (n = 10) were working part-time. These women had a range of breast cancer types and stages. Most participants had stage 1 (n = 32, 22.9%) or stage 2 (n = 67, 47.9%) breast cancer (Table 1). In the larger ACTS intervention study, there were no statistically significant differences between the study groups in demographic data or tumor type.¹⁴

Debriefing Questionnaire

The mean total score for the usual care group was

50.25 (SD 16.07). The mean subscores of the debriefing questionnaire for the usual care group ranked displayed concern for the participant's health and well-being (M 11.41, SD 3.84), support (M 11.38, SD 3.27), and the bond of shared experience (M 11.19, SD 3.75) by the ACTS study team highest. Nonspecific factors of not wanting to disappoint (M 6.00, SD 4.37) and time and attention (M 10.28, SD 3.96) by the ACTS study team were ranked lowest. Of the larger ACTS study outcomes, support (M 17.72, SD 5.04) was rated as influenced the most by the nonspecific factors (Table 2).

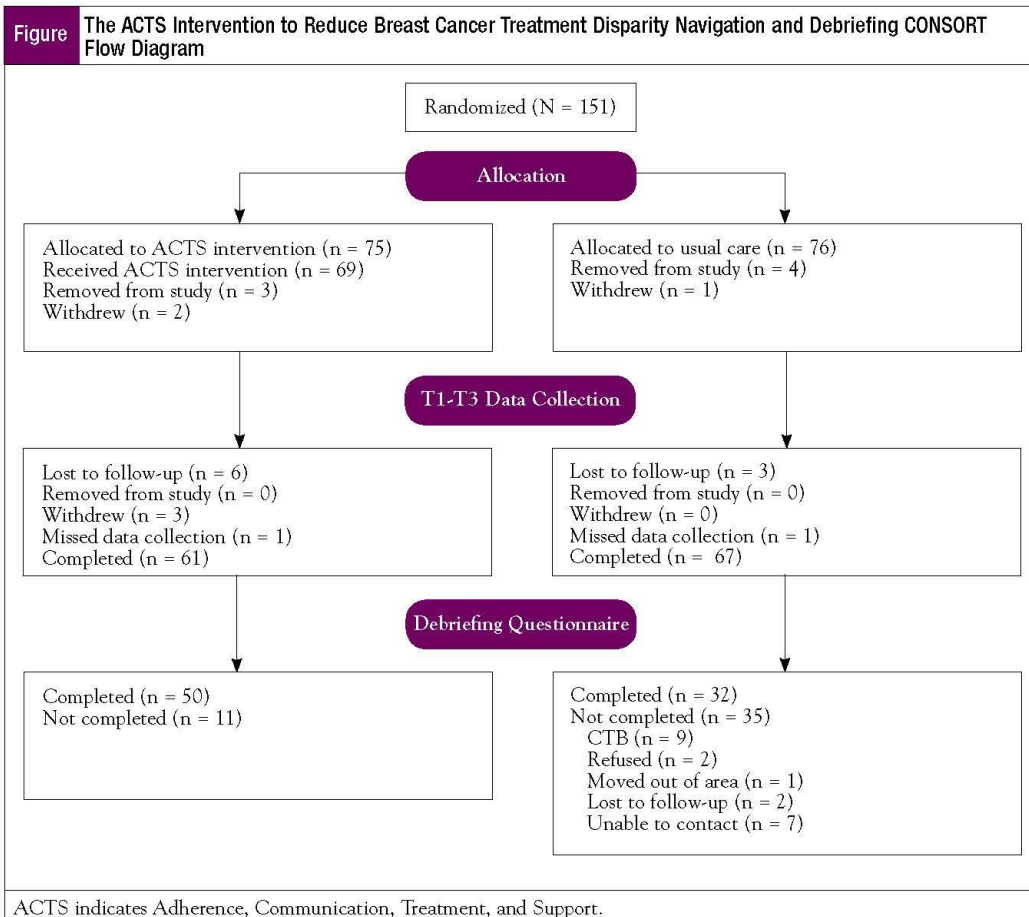
The ACTS intervention group rated displayed concern for the participant's health and well-being, support, and the bond of shared experience by the ACTS interventionist highest.

Overall, the ACTS intervention group had a lower mean total score (M 47.36, SD 15.50) and lower mean subscores than the usual care group. However, like the usual care group, the ACTS intervention group rated displayed concern for the participant's health and well-being (M 11.02, SD 3.61), support (M 10.74, SD 3.48), and the bond of shared experience (M 10.88, SD 3.40) by the ACTS interventionist highest. Likewise, not wanting to disappoint (M 5.68, SD 4.00) and time and attention (M 9.88, SD 3.67) by the ACTS interventionist were rated lowest. Additionally, the ACTS intervention group rated the study outcome of support (M 16.90, SD 5.61) as the most influenced by the nonspecific factors (Table 2). Although the usual care group had higher overall mean total and subscores, there was no significant difference between the group scores ($P = .42$).

Discussion

Study staff may have influenced the primary results of the ACTS study through relational tasks. From these results, we find that support and concern for the patient's health and well-being from either the ACTS interventionist or study staff may have influenced the study outcomes. Although these results cannot confirm the influence of the supportive nature of the study staff on study results, we suspect that it positively influenced the improved adherence to chemotherapy seen in both the usual care and intervention groups in the larger ACTS intervention study. These results suggest that the presence of peer support within

Continued on page 32



medical oncology clinics encourages adherence. Evidence for this peer support has been shown in qualitative research from the area of patient navigation in cancer care, which found that many times both navigators and patients noted the importance of relational tasks, such as support, over the instrumental interventions, or task-oriented activities of navigators.^{15,16} The relational tasks include spending time with the patient, building trust and relationships, encouragement, social support, supporting autonomy, providing comfort, effective communication, and coaching.¹⁵⁻¹⁷ The results also identified the importance of culturally matched patient navigators. Analysis of these studies points to the importance of the patient-navigator re-

lationship on the ability to build trust, develop rapport, provide psychosocial support, and increase the patient's participation in care.¹⁵

While having a racially diverse healthcare system would prevent the concern of contaminating study results through the effects of racially sensitive interventions, it is unclear if the researcher's attempts to develop a racially sensitive intervention or the combined effect of racially concordant and supportive study staff contaminated this study's findings. The presence of racially concordant study staff may have contaminated the study findings as this was an anomaly in the local healthcare system with limited racial diversity among its staff. Although the United States is an increasingly diverse na-

Continued on page 34

Table 2 Statistics of Debriefing Subscores and Total Score

	Range	Usual Care (n = 32)	Intervention (n = 50)	P Value
Support by ACTS study team	3.00-15.00	11.38 (3.27)*	10.74 (3.48)	.41
Bond of shared experience with ACTS study team	3.00-15.00	11.19 (3.75)	10.88 (3.40)	.70
Not wanting to disappoint ACTS study team	3.00-15.00	6.00 (4.37)	5.68 (4.00)	.73
Time and attention provided by ACTS study team	3.00-15.00	10.28 (3.96)	9.88 (3.67)	.64
Displayed concern for health and well-being of ACTS study team	3.00-15.00	11.41 (3.84)	11.02 (3.61)	.65
Follow-through	5.00-25.00	17.22 (5.98)	16.34 (5.71)	.51
Support	5.00-25.00	17.72 (5.04)	16.90 (5.61)	.51
Distress	5.00-25.00	15.31 (6.01)	14.12 (6.03)	.38
Debrief Total Score	15.00-75.00	50.25 (16.07)	47.36 (15.50)	.42

*Mean (standard deviation).
ACTS indicates Adherence, Communication, Treatment, and Support.

tion, ethnic and racial minorities are drastically under-represented in the health professions. A more racially and ethnically concordant healthcare workforce would allow for a more inclusive healthcare environment for underserved populations as well as allow for greater connections and communication between patients and their providers.^{18,19} Realization of a more diverse healthcare

unavoidable because once negative study results were appreciated and the possible etiologies were discussed, the need for a debriefing of the usual care group was made apparent. While the questionnaire was self-report and investigator initiated, it was based on well-established literature.²⁻⁵ Lastly, this study only described the debriefing questionnaire results and compared the results between groups; there was no assessment of the influence of these results on the study outcomes.

The results of this study add to the evidence for the need to further research peer support and other supportive interventions in cancer care, especially for minority and underserved groups.

workforce would create the foundation from which to conduct more inclusive and representative research on health interventions.

Design Considerations

There were several considerations in the design of this secondary study. The difference in debriefing questionnaire completion time points between the study groups may have impacted study results, including a smaller sample size in the usual care group. However, this was

Conclusion

The results of this study add to the evidence for the need to further research peer support and other supportive interventions in cancer care, especially for minority and underserved groups. Furthermore, as behavioral and health science researchers are called upon to produce efficacious disparity-eliminating interventions, the need for an honest discussion regarding the presence and impact of nonspecific factors grows increasingly important. ✱

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APPENDIX B

PERMISSION LETTER AND PRELIMINARY WORK MANUSCRIPT #2

Sarah F. Gallups
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June 14, 2018

Renée Matthews
Editor
Journal of Community and Supportive Oncology
2275 Research Boulevard
Suite 400
Rockville, MD 20850

Dear Ms. Matthews:

This letter will confirm our recent e-mail exchange. I am completing a doctoral dissertation at the University of Pittsburgh entitled "Identifying the Interpersonal Communication Components of Breast Cancer Care Patient Navigation." I would like your permission to reprint in my dissertation excerpts from the following:

Gallups, S. F., Copeland, V., Rosenzweig, M. Q. (2017). Economic hardship among patients with advanced cancer. *Journal of Community and Supportive Oncology*, 15 (3), e163-e169.

The excerpts to be reproduced include the entire article. The full article will be reprinted as an appendix. This article and the work it represents is foundational to my dissertation, so rather than retyping it and self-plagiarizing, I want to have the published article included. Full and clear credit will be given to JCSO as the publisher and copywriter of the article.

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If these arrangements meet with your approval, please sign this letter where indicated below and return it to me. Thank you very much.

Sincerely,

A handwritten signature in cursive script that reads "Sarah Gallups". The signature is written in dark ink and is positioned at the bottom left of the page, below the typed name "Sarah F. Gallups".

Sarah Gallups, RN, BSN, MPH

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE:

Renée Matthews.

Renée Matthews, Editor

Date: June 14, 2018

Perceived financial hardship among patients with advanced cancer

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Background Patients with advanced cancer experience distress in many forms. Perceived financial hardship is increasingly recognized as a toxicity of cancer, and much has been written about it in general – what it is, what causes and aggravates it, the implications on patient outcomes and cost and quality of care/life, and possible interventions to ease the impact on patients. However, it has not been extensively considered in patients with advanced cancer.

Objective To describe the financial challenges of persons with advanced cancer, and the association of financial distress with quality of life, symptom severity, and overall cancer-related distress.

Methods This is a cross-sectional, comparative, descriptive study of 100 patients with advanced cancer in outpatient medical oncology clinics in Western Pennsylvania. Five instruments measured patient demographics, symptom severity, quality of life, perceived financial hardship, and overall cancer-related distress. Descriptive statistics and correlation coefficients were used. Quality of life, symptom severity and cancer-related distress were compared with high or low levels of perceived financial hardship using a 2-sample t test.

Results The mean age of participants was 63.43 years ($n = 100$). Perceived financial hardship was mildly correlated with overall cancer-related distress ($r, 0.409; P < .001$), symptom distress ($r, 0.409; P < .001$), and overall quality of life scores ($r, 0.323; P < .001$). In addition, patients experiencing higher levels of perceived financial hardship experienced worse quality of life overall ($P = .002$), higher levels of cancer-related distress ($P < .001$), and worse symptom distress ($P < .001$).

Limitations Cross-sectional design

Conclusions These results illuminate our understanding of disparities that may be present in end of life care. Perceived financial hardship appears to negatively influence symptom severity and quality of life. These results illuminate targeted areas for cancer-related distress mitigation.

Funding/sponsorship The Center on Race and Social Problems, University of Pittsburgh

The American Cancer Society has identified a disparity in cancer death rates, noting that persons with lower socioeconomic status have higher rates of mortality.¹ This is attributed to many factors, but it is largely owing to the higher burden of disease among lower-income individuals.¹ A component of this disease burden is measured by assessing the patient-reported outcome of cancer-related distress. The National Comprehensive Cancer Network (NCCN) Distress Management Guidelines have defined distress as “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social and/or spiritual nature that may interfere with the ability to cope with cancer, its physical symptoms and its treatment.”²

Financial hardship related to cancer diagnosis and treatment is increasingly being recognized as an important component of disease burden and distress. The advancements in costly cancer treat-

ments have produced burdensome direct medical costs as well as numerous indirect costs that contribute to perceived financial hardship.^{3,4} These indirect costs include nonmedical expenses such as increased transportation needs or childcare, loss of earnings, or loss of household income due to caregiving needs.³ Moreover, indirect costs are often managed by patients and families through their use of savings, borrowing, reducing leisure activities, and selling possessions.³ Even though efforts to increase health coverage, such as the Affordable Care Act, have reduced the rates of individuals who are uninsured, persons with cancer who have insurance also face challenges because they cannot afford copays, monthly premiums, deductibles, and other high out-of-pocket expenses related to cancer treatment that are not covered by their insurance such as out-of-network services or providers.⁵⁻⁷

Thus, financial hardship may have an impact

Accepted for publication April 13, 2017. Correspondence: Sarah Gallups, MPH, RN; sfg11@pitt.edu. Disclosures: The authors report no disclosures or conflicts of interest. JCSO 2017;15(3):e163-e169. ©2017 Frontline Medical Communications. doi: <https://doi.org/10.12788/jcso.0341>

on several areas of a patient's life and well-being, but the effects are commonly undetected.⁸⁻¹⁰ Research has established that financial strain can influence treatment choices and adherence to therapy.¹¹ Furthermore, the effects of financial strain have been identified across the cancer care continuum, from diagnosis through survivorship, suggesting a bidirectional relationship between financial strain and well-being.¹¹ Financial strain may reduce patient quality of life and worsen symptom burden because of the patient's inability to access needed care, poor social supports, and/or increased stress.¹¹⁻¹² These worsening outcomes may also increase the use of financial reserves and affect their ability to work.^{7,11} Financial difficulties may also be associated with anxiety and depression, leading to worse quality of life and greater distress and symptom burden.¹² Identifying groups at high risk for financial strain is crucial to ensure that resources are available to assist these populations.¹³ This burden can be even more pronounced in minority and underserved patients with cancer.⁷ Patients with advanced cancer are especially vulnerable to the burden of increased costs because of the use of expensive targeted therapies; their improved survival, which extends the time of expenditure; and increased use of financial reserves.⁹ Financial hardship in patients with advanced cancer is not well understood or characterized,⁹ which is why this study aimed to better quantify distress in advanced stage cancers by describing:

- A cohort of patients with advanced cancer and their levels of quality of life, symptom distress, cancer-related distress and perceived financial hardship;
- The relationship between perceived financial hardship, quality of life, symptom distress and overall cancer-related distress; and
- Quality of life, symptom distress, and overall cancer-related distress according to level of perceived financial hardship.

Methods

This study is a cross-sectional, descriptive, comparative study of distress, including perceived financial hardship, among patients with advanced cancer who were receiving palliative care treatment in two outpatient medical oncology clinics in Western Pennsylvania. The data were collected during May 2013–November 2014. The study protocol was approved by the Institutional Review Board at the University of Pittsburgh. Eligible participants had to be 18 years or older and have an advanced solid tumor of any kind, with a prognosis of 1 year or less confirmed by a physician or clinic nurse practitioner/physician assistant, and be able to read and understand English at the fourth-grade level. The sample was recruited from two clinics at the University of Pittsburgh Cancer Institute, a National Cancer Institute-designated Comprehensive Cancer Program.

Measurements

Sociodemographic factors. These were measured using an investigator-derived Sociodemographic Questionnaire, a 12-item form that includes variables such as age, race, marital status, cancer type, religion and spirituality, employment status, years of education, health insurance status, and income level.

Cancer-related distress. The NCCN Distress Thermometer is a self-report visual analog scale (0, no distress; 10, great distress) formed in the shape of a thermometer combined with a problem list that is often used in outpatient cancer settings for reporting of cancer-related distress.¹⁴⁻¹⁶ The sensitivity, specificity and convergent validity with the Brief Symptom Inventory and the Hospital Anxiety and Depression Scale have been established and appropriate cut-off score of the distress thermometer identified.¹⁴⁻¹⁶ A score of 4 or above indicates a clinically significant level of distress.¹⁴⁻¹⁶

Symptom distress. The McCorkle Symptom Distress Scale was developed in 1977 based on interviews that focused on the symptom experiences of patients. Psychometric testing among patients with cancer using the modified Symptom Distress Scale revealed high reliability (Cronbach alpha, 0.97).¹⁷ The instrument is a 13-item Likert scale (1–5) assessing the severity of distress experienced by a symptom. Total scores range from 13 to 65, where a higher score indicates greater distress. Moderate distress is indicated with a score of 25–33, and a score above 33 indicates severe distress, identifying the need for immediate intervention.¹⁷

Quality of life and spiritual well-being. The Functional Assessment of Cancer Therapy (FACT-G) is used to assess general cancer-related quality of life. It has four subscales: physical, emotional, social and family, and functional well-being, with a total score that ranges from 0–112, where higher scores show higher quality of life. The Spiritual Distress Well-Being questionnaire was used alongside the valid FACT-G assessment.^{18,19} The Spiritual Well-Being Short Form was developed with an ethnically diverse population and adds 12 items to the FACT-G. The items do not necessarily assume a faith in God, allowing a wide flexibility in application and tapping into issues such as faith, meaning, and finding peace and comfort despite advanced illness. Higher scores on the Spiritual Well-Being subscore (range, 0–48) are correlated with higher scores of quality of life. The possible scores for the combined FACT-G and Spiritual Well-Being assessment range from 0–160, with higher scores showing higher quality of life.

Economic hardship. Perceived financial hardship was measured using Barrera and colleagues' Psychological Sense of Economic Hardship Scale.²⁰ The scale consists of 20-items

broken down into 4 subscales: financial strain, inability to make ends meet, not enough money for necessities, and economic adjustments.²⁰ Economic adjustments in the 3 months before administration of the questionnaire were assessed with 9 Yes or No items, such as *added another job*, *received government assistance*, or *sold possessions to increase income*. The subscale of not enough money for necessities was assessed with seven 5-point scale items in which respondents noted whether they felt they had enough money for housing, clothing, home furnishings, and a car over the previous 3 months. Inability to make ends meet included two 5-point scale items that assessed the difficulty in meeting financial demands in the previous 3 months. Financial strain consisted of two 5-point scale items concerned with expecting financial hardships in the coming 3 months. Scores can range from 20-73, with a higher score indicating worse economic hardship.

Data collection and analysis

In-person data collection occurred in the clinical waiting area before the clinician visit or in the treatment room with the patient using a consecutive, convenience sample. The nursing staff checked the clinic lists daily for possible patient participants. Patients with metastatic cancer were identified and then approached for consent. After we had received the patient's consent, the administration of the instruments took about 20 minutes to complete. The data were then entered and verified in REDCap (Research Electronic Data Capture), which is hosted at the University of Pittsburgh.²¹ The levels of symptom distress, quality of life, perceived financial hardship, and cancer-related distress were described through continuously measured variables. Descriptive statistics, measures of central tendency (mean and median), and dispersion (standard deviation and range), were obtained for the subscales and total scores. Correlation analysis was used to describe the relationship between perceived financial hardship and quality of life, symptom distress, and cancer-related distress. These primary outcome variables were further explored according to the level of dichotomized perceived financial hardship using mean score as the cut point. Independent sample *t* tests were used to compare patients experiencing high perceived financial hardship with those experiencing low perceived financial hardship.

Results

In all, 100 patients participated in the study. Any missing data points were replaced with the mean score for that variable, although this was minimal in this study. Most of the participants were women (67%), and the average age of the participants was 63.43 years (SD, 13.05; Table 1). Of the total number of participants, 73% were white, 26% were black, and 1% were Asian. Most of the participants were either retired and not working (39%) or disabled or unable

TABLE 1 Sociodemographic characteristics of the participants (N = 100)

Characteristic	Value
	Mean no. years (SD)
Age at consent	63.43 (13.05)
Formal education	13.48 (2.78)
	Percentage
Gender	
Male	33
Female	67
Race	
White	73
African American/black	26
Asian	1
Type of cancer	
Breast	25
Gynecologic	10
Lung	19
Colon/rectal	15
Brain	1
Pancreatic	5
Kidney	1
Prostate	5
Other	19
Gross annual household income, US\$	
<10,000	13
10,000-<13,000	6
13,000-<20,000	16
20,000-<30,000	14
30,000-50,000	24
>50,000	12
Refused to reveal	15
Current employment status	
Full time	15
Part time (<35 h)	3
Retired, not working at all	39
Retired, employed full/part time	3
Disabled/unable to work	34
Other	6
Marital status	
Never married	24
Currently married	42
Living with partner/significant other	4
Widowed	14
Separated	2
Divorced	13
Other	1
Importance of religion/spirituality	
Not important at all	10
Somewhat important	19
Extremely important	71
Insurance status	
Public/private insurance	99
No insurance	1

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TABLE 2 Summary statistics of measured outcome variables (N = 100)

Outcome variable	Score range	Average score (SD)
NCCN Distress Thermometer ^c	0-10	4.16 (3.26)
McCorkle Symptom Distress Scale ^a	13-65	25.45 (9.34)
FACT-G ^b	0-112	73.77 (19.40)
Physical Well-Being subscale	0-28	17.35 (7.50)
Social/Family Well-Being subscale	0-28	24.21 (5.25)
Emotional Well-Being subscale	0-28	16.34 (5.42)
Functional Well-Being subscale	0-28	15.87 (6.78)
Spiritual Well-Being Short Form	0-48	35.20 (9.25)
Combined FACT-G, Spiritual Well-Being	0-160	108.97 (26.07)
Psychological Sense of Economic Hardship Scale ^d	20-73	35.70 (13.87)
Financial Strain subscale	2-10	3.44 (2.36)
Inability to Make Ends Meet subscale	2-10	5.73 (1.91)
Not Enough Money for Necessities subscale	7-35	16.43 (8.92)
Economic Adjustments subscale	9-18	10.63 (2.70)

FACT-G, Functional Assessment of Cancer Therapy-General; NCCN, National Comprehensive Cancer Network

^aHigher score indicates greater distress. ^bHigher score indicates better quality of life. ^c0 = no distress, 10 = great distress; ^d≥4 indicates a clinically significant level of distress. ^eHigher score indicates worse economic hardship.

to work (34%). Almost all of the participants had some form of insurance, with 99% having either private or public health insurance. A variety of cancer types were represented in this patient population, with higher percentages of breast (25%), gynecologic (10%), lung (19%), and colon/rectal cancer (15%). Of the total number of participants, 35% had annual household incomes below \$20,000, and

50% had annual household incomes of more than \$20,000. On average, participants had 13.48 years (SD, 2.78) of formal education.

Descriptive statistics for the primary outcome variables can be found in Table 2. The average score for cancer-related distress based on the NCCN Distress Thermometer tool was 4.16 (SD, 3.26). The average score for the McCorkle Symptom Distress measurement was 25.45 (SD, 9.34). For quality of life, the average FACT-G total score was 73.77 (SD, 19.40). Of the FACT-G subscale average scores, physical well-being was 17.35 (SD, 7.50), social/family well-being 24.21 (SD, 5.25), emotional well-being 16.34 (SD, 5.42), and functional well-being 15.87 (SD, 6.78). Participants' average score for the spiritual well-being measure was 35.20 (SD, 9.25) and the combined FACT-G and spiritual well-being average score was 108.97 (SD, 26.07). The total average score for perceived financial hardship was 35.70 (SD, 13.87), with subscale average scores of 3.44 (SD, 2.36) for financial strain, 5.73 (SD, 1.91) for inability to make ends meet, 16.43 (SD, 8.92) for not enough money for necessities, and 10.63 (SD, 2.70) for economic adjustments.

We conducted a bivariate correlation analysis to assess the relationship between perceived financial hardship and three other primary outcome variables (Table 3). These analyses showed significant low to moderate correlations with overall cancer-related distress (r , 0.439; P < .001), symptom distress (r , 0.409; P < .001), and overall quality of life scores (FACT-G and spiritual well-being combined score: r , -0.323; P < .001).

TABLE 3 Correlation analysis of primary outcome variables and economic hardship (N = 100)

	Psychological Sense of Economic Hardship Scale total score	McCorkle Symptom Distress Scale total score	Combined FACT-G and Spiritual Well-Being	NCCN Distress Thermometer
Psychological Sense of Economic Hardship Scale total score	1.00	—	—	—
McCorkle Symptom Distress Scale total score	0.409*	1.00	—	—
Combined FACT-G and Spiritual Well-Being	-0.323*	-0.737*	1.00	—
NCCN Distress Thermometer	0.439*	0.602*	-0.483*	1.00

FACT-G, Functional Assessment of Cancer Therapy-General; NCCN, National Comprehensive Cancer Network

*Significant at alpha <0.01

TABLE 4 Difference between group means based on level of economic hardship (N = 100)

	Level of economic hardship, mean score (SD)		P-value	Confidence interval
	High (n = 43)	Low (n = 57)		
NCCN Distress Thermometer total	6.17 (2.91)	2.65 (2.64)	<.001*	2.41–4.63
McCorkle Symptom Distress total	29.70 (9.97)	22.25 (7.44)	<.001*	4.01–10.91
FACT-G total	65.62 (19.29)	79.92 (17.23)	<.001*	-21.58–7.02
Physical Well-Being subscale	13.56 (7.63)	20.21 (6.04)	<.001*	9.36–3.94
Social/Family Well-Being subscale	22.79 (6.63)	25.28 (3.61)	.029*	-4.73–0.26
Emotional Well-Being subscale	14.77 (6.06)	17.53 (4.58)	.011*	-4.87–0.65
Functional Well-Being subscale	14.51 (6.52)	16.89 (6.84)	.082	-5.07–0.30
Spiritual Well-Being Short form total	34.40 (10.01)	35.81 (8.67)	.453	-5.13–2.30
Combined FACT-G and Spiritual	100.02 (27.50)	115.72 (22.94)	.002*	-25.73–5.67

FACT-G, Functional Assessment of Cancer Therapy-General; NCCN, National Comprehensive Cancer Network.

*Significant at alpha <0.05

Forty-three participants reporting high perceived financial hardship experienced worse quality of life overall (FACT-G and spiritual well-being; $P = .002$), worse FACT-G total scores ($P < .001$), worse physical well-being ($P < .001$), worse social/family well-being ($P = .029$), worse emotional well-being, and no significant difference for functional ($P = .082$) or spiritual well-being ($P = .453$), compared with those with lower economic hardship. In overall cancer-related distress, participants with higher perceived financial hardship reported higher levels of cancer-related distress ($P < .001$) than those with lower perceived financial hardship. For those participants reporting higher perceived financial hardship there was also worse symptom distress ($P < .001$), compared with those with lower economic hardship (Table 4).

Discussion

Overall, this report provides data to illuminate our understanding of disparities in well-being that may be present in patients with advanced cancer. Our analysis found that patients with advanced cancer who have higher perceived financial hardship have significantly higher overall cancer-related distress, symptom distress, and poorer overall quality of life. In this study's population of patients with advanced cancer, the most notable areas of economic hardship identified by participants were: not having enough money for necessities in the 3 months before the survey and the inability to make ends meet during the same time span, with difficulty paying bills and not having enough money left at the end of the month being most noteworthy among this study's patient population. Financial strain and making economic adjustment were not as notable in the category of perceived financial hardship. In regard to not

having enough money, participants most commonly cited not being able to afford everyday necessities such as food, clothing, medical care, or a home, as well as leisure and recreational activities. These findings are further supported with the positive, moderate associations between perceived financial hardship and symptom distress and overall cancer-related distress found in this cohort of patients with advanced cancer and the negative, moderately associated relationship between perceived financial hardship and overall quality of life in this study's sample. Although these findings have been confirmed in the literature on cancer-related distress, our findings add to our knowledge on both economic and cancer-related distress exclusively in patients with advanced cancer.^{9,22} The broader cancer-related distress literature has also found an association between being younger and having a lower household income as risk factors for increased financial hardship; however, the perception of financial strain and magnitude was a more significant predictor of quality of life and perception of overall well-being.^{6,8–9,12,22–23} Furthermore, patients with cancer who noted having higher financial distress typically reported decreased satisfaction with cancer care which also influenced their adherence to treatment and quality of life.²⁴

Our work now adds the important element of perceived financial hardship to the advanced cancer-related distress puzzle. We should consider integrating a financial distress assessment into routine cancer care, particularly with patients and families with advanced cancer, to proactively and routinely assess and intervene with available distress mitigating resources. Therefore, understanding the patients most likely to experience financial distress will help personalize supportive therapy. This study's results as

well as the existing literature describing financial distress support the use of comprehensive screening instruments to capture elements of financial burden beyond out-of-pocket costs.^{8,25} This screening is particularly relevant because we are increasingly recognizing that gross annual household income does not always reflect financial hardship or distress. The instrument we used for this analysis, the Psychological Sense of Economic Hardship, provides a broad view of financial toxicity including the specific components of financial strain, the inability to make ends meet, not having enough money for necessities, and economic adjustments experienced by patients with advanced cancer.²⁰ Another measure to evaluate financial toxicity among patients with cancer includes the Comprehensive Score for Financial Toxicity (COST), which is a widely used patient-reported outcome measure. It was developed with input from both patients and oncology experts.²⁵ Use of a financial toxicity assessment tool adds to our understanding of the economic financial burden experienced by patients with cancer, specifically those with advanced cancer.

Tucker-Seeley and Yabroff have identified several areas in which the research agenda for financial toxicity should focus, including: documentation of the socioeconomic context among patients across all areas of the cancer care continuum, further identification and characterization of at risk populations to address health disparities, and the inclusion of cost discussions in the health care context.²⁶ Furthermore, research is needed to identify key areas to target for interventions addressing financial toxicity, such as addressing lack of financial resources to cover the cost of cancer care, focusing on managing or preventing the distress that results from a lack of financial resources, or addressing coping behaviors used by families to manage the financial burden of cancer care.²⁶ Although cost discussions between health care providers and patients have been identified as important in reducing the financial burden of cancer care, the content, timing, and goals of those discussions still need to be better articulated for different patient populations, including patients with advanced cancer.^{3,27-28} In addition, resources such as social workers, patient navigators, or financial counselors have been identified as effective in assisting patients with financial planning and accessing community resources to address financial burden and assistance.⁴

Design considerations

This study has limitations that need to be noted. Its cross-sectional design does not allow for the analysis of causal inferences. In addition, certain groups were underrepresented in this study's sample, including uninsured patients, men, and some minority groups, which may have underestimated the amount of financial burden experienced by patients with advanced cancer. The lack of representative-

ness of uninsured individuals may be a result of the eligibility of persons with advanced cancer for Medicaid. However, a strength of this study is its ability to increase the representativeness of African American/black patients in the study of advanced cancer and financial hardship. In our study, just over a quarter of the participants (26 of 100; 26%) were black/African American, compared with the US Census Bureau's national census level of 13.3% and 13.4% in Allegheny County, Pennsylvania.²⁹

The lack of employed participants in this study could be because many were not able to work because of the advanced stage of their disease. The low level of partnered status is a limitation, although one study site was a low-income hospital where one generally tends to see higher levels of unpartnered status. This study did not control for demographic information such as gender or age, thus, the relationships between the primary outcome variables and financial hardship may be overestimated. Moreover, this analysis of financial distress is limited to the context of the United States due to our lack of universal health care and unique payment system. Although we included only patients who were in the palliative phase of cancer treatment, no medical record review was conducted to determine previous cancer history and treatments, which might have provided more insight into other financial loss or cost of cancer treatment. Furthermore, we note that it can be difficult to prognosticate with accuracy and identify that some patients with advanced cancer may have been excluded from the study due to the inclusion criteria of less than 1 year of survival.

Conclusion

Perceived financial hardship is an important assessment of the burden placed on patients due to the cost of disease; and is a good start in assessing indirect costs that patients take on when coping with advanced stages of cancer and can shed light on an aspect of distress experienced by this patient population that is not commonly addressed. Subjective measures of perceived financial hardship complement objective measures that are commonly indicative of economic resources and can further our understanding of the impact of financial distress experienced by patients with cancer. Further study of financial impacts of advanced cancer as well as predictors of financial distress are essential to the early identification of financial hardship and the development of interventions to support those at high risk or experiencing financial distress.

Acknowledgments

The authors acknowledge the patients and staff at the UPMC Mercy Cancer Center in Pittsburgh, Pennsylvania, who made this study possible, and Peggy Tate for her role in data collection. They also recognize the support of the Robert Wood Johnson Foundation through the Future Nursing Scholars program. They would also like to acknowledge that permission was granted for the use of the Psychological Sense of Economic Hardship study instrument.

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APPENDIX C

IRB APPROVAL FOR STAKEHOLDER ENGAGEMENT STUDY



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
<http://www.oirb.pitt.edu>

Memorandum

To: Sarah Gallups
From: IRB Office
Date: 4/18/2017
IRB#: PRO17020389
Subject: Identifying Interpersonal Components of Patient Navigation: Stakeholder Engagement

The above-referenced protocol has been reviewed by the University of Pittsburgh Institutional Review Board. Based on the information provided to the IRB, this project includes no involvement of human subjects, according to the federal regulations [§45 CFR 46.102(f)]. That is, the investigator conducting research will not obtain information about research subjects via an interaction with them, nor will the investigator obtain identifiable private information. Should that situation change, the investigator must notify the IRB immediately.

Given this determination, you may now begin your project.

Please note the following information:

- If any modifications are made to this project, use the "**Send Comments to IRB Staff**" process from the project workspace to request a review to ensure it continues to meet the determination.
- Upon completion of your project, be sure to finalize the project by submitting a "**Study Completed**" report from the project workspace.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX D

IRB APPROVAL FOR DISSERTATION STUDY



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)
<http://www.irb.pitt.edu>

Memorandum

To: Sarah Gallups
From: IRB Office
Date: 11/1/2017
IRB#: [PRO17080033](#)
Subject: Identifying the Interpersonal Communication Components of Breast Cancer Care Patient Navigation

The University of Pittsburgh Institutional Review Board reviewed and approved the above referenced study by the expedited review procedure authorized under 45 CFR 46.110 and 21 CFR 56.110. Your research study was approved under:

45 CFR 46.110.(6)

45 CFR 46.110.(7)

The IRB has approved the waiver for the requirement to obtain a written informed consent for all procedures.

The risk level designation is Minimal Risk.

Approval Date: 11/1/2017
Expiration Date: 10/31/2018

For studies being conducted in UPMC facilities, no clinical activities can be undertaken by investigators until they have received approval from the UPMC Fiscal Review Office.

Please note that it is the investigator's responsibility to report to the IRB any unanticipated problems involving risks to subjects or others [see 45 CFR 46.103(b)(5) and 21 CFR 56.108(b)]. Refer to the IRB Policy and Procedure Manual regarding the reporting requirements for unanticipated problems which include, but are not limited to, adverse events. If you have any questions about this process, please contact the Adverse Events Coordinator at 412-383-1480.

The protocol and consent forms, along with a brief progress report must be resubmitted at least one month prior to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00000600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

APPENDIX E

PATIENT RECRUITMENT FLYER

Have you ever been diagnosed with breast cancer and worked with a patient navigator?

You could help researchers at the University of Pittsburgh School of Nursing learn more about patient navigation and ways to improve patient experiences.

We are looking for men and women ages 21 and older who have or have had breast cancer.



Participants will be compensated for online surveys and one in-person meeting

CONTACT US TO LEARN MORE:

Sarah Gallups RN , BSN, MPH

University of Pittsburgh School of Nursing

Phone: (412) 301-3977

Email: Sfg11@pitt.edu

APPENDIX F

PATIENT NAVIGATOR AND ADMINISTRATOR RECRUITMENT FLYER

Are you a patient navigator or administrator working with breast cancer patients?

You could help researchers at the University of Pittsburgh School of Nursing learn more about patient navigation and ways to improve patient experiences in Western Pennsylvania.



Participants will be compensated for online surveys and one in-person meeting regarding personal experiences in assisting patients to navigate the health care system.

CONTACT US TO LEARN MORE:

Sarah Gallups RN , BSN, MPH

University of Pittsburgh School of Nursing

Phone: (412) 301-3977

Email: Sfg11@pitt.edu

APPENDIX G

DEMOGRAPHIC QUESTIONNAIRE

Sociodemographic Questionnaire

1. What is your age?

2. What is your race/ethnicity?

- a. White or Caucasian
- b. Black or African American
- c. Hispanic, Latino or Spanish origin
- d. Asian
- e. Other:

3. What is your highest level of education achieved?

- a. Elementary school or less
- b. Some middle school/junior high
- c. Some high school
- d. High school graduate (received diploma, GED, or equivalent)
- e. Some college or technical school
- g. Associates degree
- h. 4-year college degree
- i. Master's, Professional, or Doctoral degree

4. How many years experience do you have as a patient navigator or patient navigator administrator? (leave blank if not applicable).

5. What is your annual household income level?

(Select only one.)

- a. \$24,999 or less
- b. \$25,000 to \$34,999
- c. \$35,000 to \$49,999
- d. \$50,000 to \$74,999
- e. \$75,000 or more
- f. I prefer not to answer

APPENDIX H

PATIENT-NAVIGATOR RELATIONSHIP SCALE

Identifying the Interpersonal Communication Components of Breast Cancer Care Patient Navigation



Patient-Navigator Relationship

Please rate on a scale of 1 to 5 the importance of each item to facilitating a positive relationship between the patient and the navigator:

1 = not important; 2 = somewhat important; 3 = moderately important; 4 = very important; 5 = extremely important

Not Important			Extremely Important			
1	2	3	4	5		
1	2	3	4	5	1.	Is there anything we can do for you to make your treatment better?
1	2	3	4	5	2.	Always stop whatever busy work is being done when the patient approaches to give them full attention.
1	2	3	4	5	3.	Does not discount patients' fears or worries, but addresses them with careful explanations of what to expect during an appointment while offering support.
1	2	3	4	5	4.	Provide information on various services and supports available in the cancer center and health system (dietitian, social worker, integrative oncology).
1	2	3	4	5	5.	Assess barriers to care.
1	2	3	4	5	6.	Initially discusses on the phone, the type of cancer and receptor status. If the patient is not receptive to discussing treatment, then details are discussed at their visit with the breast surgeon.
1	2	3	4	5	7.	Do not discuss politics or religion.
1	2	3	4	5	8.	I always had good information about what I was going through.
1	2	3	4	5	9.	Provides comfort, such as holding the patient's hand during a biopsy or office appointment, sitting with the patient, or meeting the patient at the hospital if they are apprehensive, assuring them that they are not alone.
1	2	3	4	5	10.	Provide and connect patients with support groups or other emotional support resources.
1	2	3	4	5	11.	Develop peer to peer match for patient.
1	2	3	4	5	12.	Supply easy to read information on diagnosis and coping.
1	2	3	4	5	13.	Being sincere.
1	2	3	4	5	14.	Whether or not patient navigation can be offered in a patient's primary language.
1	2	3	4	5	15.	Always have a personal interest in the patient, their family and kids.
1	2	3	4	5	16.	Establish the rapport with each newly diagnosed patient as early as possible.
1	2	3	4	5	17.	It is never about the navigator or nurse or staff person, it is only about the patient.
1	2	3	4	5	18.	Listens carefully to what the patient wants to say and needs, even if it's not directly related to screening or diagnosis, whenever possible. A lot of the times they feel isolated and don't have many other people to talk to or don't feel they can share with other people.
1	2	3	4	5	19.	Be comfortable with silence and tears.
1	2	3	4	5	20.	Make sure the patient with a new diagnosis has ALL the information they need to make an informed choice about their care (surgical options, genetic testing, neoadjuvant chemotherapy, adjuvant chemotherapy, etc)- no regrets!
1	2	3	4	5	21.	Encourage and help the patient to speak with their doctor and ask questions as well as utilize resources.
1	2	3	4	5	22.	Don't make unrealistic statements/promises suggesting it will definitely be "okay" or "fine".

1	2	3	4	5	23.	Prepare the patient for end of treatment including a warm handoff to the survivorship navigator. Introduce them before the last treatment, making sure the patient knows they can continue to contact you as they return to a new "normal".
1	2	3	4	5	24.	Always introduce yourself to them and it's good to ask the name of the spouse or other family members who accompanies the patient.
1	2	3	4	5	25.	Inform you about the easiest and best way to go about it (For example, my navigator would let me know that you have to fill out this by this time and had me the paperwork. She even added sticky notes about where you need to sign.)
1	2	3	4	5	26.	Provide and connect patients with community or other local resources, such as the American Cancer Society's 'Look Good...Feel Better' or the Reach to Recovery program.
1	2	3	4	5	27.	She set up rides for me, I was able to go with Medic Rescue.
1	2	3	4	5	28.	Provide patient contact information for follow-up, future questions or concerns and encourage to contact as needed.
1	2	3	4	5	29.	If children come to treatment or appointments, provide them with coloring or activity books, Play-Doh, etc...or appropriate DVDs with DVD player to borrow.
1	2	3	4	5	30.	Being there for all my appointments.
1	2	3	4	5	31.	Explains medical terminology in layman's terms.
1	2	3	4	5	32.	They let you know what is going to work or not or what is available or not right off the bat.
1	2	3	4	5	33.	I know how you feel.
1	2	3	4	5	34.	Check understanding of treatments and treatment options.
1	2	3	4	5	35.	Answers any questions the patient has and if they don't know, they get the answers.
1	2	3	4	5	36.	Help them through the process of losing hair (offer donated hand made caps and scarves, where they can get a free wig or purchase if they prefer).
1	2	3	4	5	37.	I am here for you. If there is anything you need please call or email.
1	2	3	4	5	38.	Follows up with patient on a regular basis and certain time points throughout their treatment.
1	2	3	4	5	39.	Call the patient prior to their first visit to acclimate them to simple things and alleviate fears (how to get here or help with transportation, where to park, what to expect when they walk in the door, who will greet them and escort them upstairs, where to go).
1	2	3	4	5	40.	Direct and inform the patient in a caring and compassionate way through their treatment plan.
1	2	3	4	5	41.	Let the patient know that it is okay to feel whatever they feel (sad, angry, whatever it is), it is all normal. A positive attitude is not always possible and that is okay.
1	2	3	4	5	42.	Keep acutely connected to the provider's notes in the electronic medical record, as to anticipate patient reactions.
1	2	3	4	5	43.	She was very positive.
1	2	3	4	5	44.	I am here to make your life as easy as possible during this difficult time.
1	2	3	4	5	45.	Have good eye contact with the patient and their family members.
1	2	3	4	5	46.	Advocates on behalf of the patient with intimidating financial issues that come up with healthcare system (financial assistance, incorrect billing, collections, insurance, etc).
1	2	3	4	5	47.	Tell patients to take one step at a time throughout this process, especially for those going through chemotherapy. Don't clog your mind with too many thoughts or questions. Just focus on one thing at a time.
1	2	3	4	5	48.	When I first talked to a patient navigator, she told me I would get disability in 6 weeks due to compassionate allowance. What she should have said is I would have a determination in 6 weeks. It was almost 7 months until I got my benefits.
1	2	3	4	5	49.	Humor offers a light moment to break the tension, a "mental pause".
1	2	3	4	5	50.	Providing visual resources to the patient (touring the cancer center, showing them what a port looks like, etc).
1	2	3	4	5	51.	They offer assurance that everything is going to workout and that there is

					help.
1	2	3	4	5	52. Very prompt responses with email and phone.
1	2	3	4	5	53. Patient navigator needs to be immersed and informed on the patients' disease specific diagnosis.
1	2	3	4	5	54. Navigators not given any training or guidelines.
1	2	3	4	5	55. Be encouraging.
1	2	3	4	5	56. She came in and she really cared about the patient, not just doing their job. She would ask me how I'm doing.
1	2	3	4	5	57. Actively listens.
1	2	3	4	5	58. The patient navigator gives the patient educational information about diagnosis and treatments and helps you understand what's going on with your type of cancer.
1	2	3	4	5	59. Be aware of non-verbal communication.
1	2	3	4	5	60. Informing the patient of "bad pathology results".
1	2	3	4	5	61. Provide a purse of hope or satchel of care with a nice note.
1	2	3	4	5	62. Don't be afraid to offer genuine care and concern for a patient, it is okay to show your human side.
1	2	3	4	5	63. Talking to the patient in a rushed or hurried manner.
1	2	3	4	5	64. My patient navigator was very empathetic.
1	2	3	4	5	65. Assist with social work and billing in terms of arranging home care and authorizations for medications/treatments.
1	2	3	4	5	66. From the very beginning they provide support and show they are with you at every step, helping you with anything that you may need during your cancer journey.
1	2	3	4	5	67. Talk to the patient while sitting at their level.
1	2	3	4	5	68. Be the voice of the patient at breast patient conferences. You may be the only one she confided in that she has a spouse that she is the sole caregiver for, no one else may know, but it could change treatment recommendations.
1	2	3	4	5	69. She was available. "As soon as I checked in and asked to see her during my treatment, before my treatment was over I would see her."
1	2	3	4	5	70. I don't always share that I am also a survivor, but when it may help the patient to not feel so alone or that the future is hopeless, I will let them know.
1	2	3	4	5	71. Provide emotional support.
1	2	3	4	5	72. I am here as support to you and your family.
1	2	3	4	5	73. Always courteous and polite.
1	2	3	4	5	74. Ask open-ended questions.
1	2	3	4	5	75. Help the patient with family concerns, how to tell the children, supportive info and hints for the caregivers, even how to ask friends to help with little things.
1	2	3	4	5	76. Telling a patient you will call them back and then forgetting to do so.
1	2	3	4	5	77. I am sorry you are going through this.
1	2	3	4	5	78. Act as resource to communicate with various care team members.
1	2	3	4	5	79. Being a stable contact from beginning of treatment until the end.
1	2	3	4	5	80. Providing support and information about programs that might help them financially.
1	2	3	4	5	81. Directs patients to reputable websites to obtain valuable information.
1	2	3	4	5	82. After informing the patient of their path results on the phone, facilitate an appointment for them with a breast surgeon.
1	2	3	4	5	83. Provides verbal as well as written information and resources to the patient.
1	2	3	4	5	84. Asks if the patient has a good support system at home or with friends.
1	2	3	4	5	85. When initially told that they have breast cancer, patients become acutely aware of their mortality; therefore, the cancer diagnosis needs to be immediately categorized to decrease those "wild eye emotions".

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